

**Caring for an Intellectually Disabled Child:
The Family Experiences.**

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Abstract

This study explored the experiences of parents who have a child with an Intellectual Disability. It also examined parents' experiences of the use of respite care. I work in the Intellectual Disability area and this was a motivation for carrying out this research. Another motivating factor is the paucity of research in this area.

A qualitative research approach was chosen for this study as the researcher believed this was the best method to learn of the personal and unique experiences of families. A purposeful sampling technique was used and ten parents participated in the study, all of whom have a child with an Intellectual Disability and who avail of respite care services. The sample consisted of nine mothers and one father. A semi-structured interview was conducted with each parent and the data was analysed using thematic analysis.

This study found that parents viewed the care of a child with an Intellectual Disability as both demanding and rewarding. The parents experienced stress and felt they were isolated in their caring role. Parents were concerned what the impact of caring for a child with an Intellectual Disability would have on their other siblings, in terms of care and the responsibilities placed on them. On the other hand, parents described the child with the Intellectual Disability as the life and soul of the family that they would not want this to change. Other findings from the study indicated that parents didn't receive enough respite care for their child and also that the care they received didn't occur when most needed but it was offered as it became available from the service provider. Another finding from the study was that parents were totally unaware of what actually occurred during the time their child was in respite care. The parents were also unaware of the qualifications of the staff offering this service. The parents also stressed that they were worried about future care needs for their Intellectually Disabled child. However, despite this worry only one parent was actively researching possible future care facilities.

This was a small piece of research that highlights the demands on parents of caring for a child with an Intellectual Disability and the shortfalls in respite service delivery. The research points to the need for more collaboration between service providers and service users. It also highlights supports these parents identified as important to them

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Declaration

This thesis is submitted to the school of Business and Social Sciences in fulfilment of the requirements for the Masters of Arts in Applied Social Care. This is my own work except where otherwise stated and acknowledged by references.

Candidate:**Date:**

Abbreviations

Autism Spectrum Disorder (ASD)

Department of Health and Children (DoHC)

Domiciliary Care Allowance (DCA)

FETAC Further Education and Training Awards Council (FETAC)

Health Information and Quality Authority (HIQA)

Health Service Executive (HSE)

Intellectual Disability (ID)

Intelligence quotient (IQ)

Learning Disability (LD)

Personal centered planning (PCP)

Quality and Qualifications Ireland (QQI)

World Health Organisation (WHO)

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1 Chapter one

The research question examined was “Caring for an Intellectually Disabled Child: The Family Experiences”

This first chapter describes the current study and the reasons for conducting it. It also gives an overview of the other four chapters of the thesis.

The study was conducted in order to gain an insight into caring for an intellectually disabled child and the experiences. The study also examines respite care, parents’ knowledge of respite and their experiences of using it. I choose this research area as I am currently working within the Intellectually Disability field and also because there is little published research in this area from an Irish perspective.

Chapter two presents the literature review. This review covers topics such as the evolution in our understanding of Intellectual Disability, the medical and social models of service delivery. The review also outlines demographics in relation to disability in the Irish context. The main body of the review looks at the published literature in relation to the impact on parents and families of caring for a child with an Intellectual Disability. This examines areas like time demands, financial impacts and isolation among parents. The review also examines supports available to families from family and from respite care. Models of respite care delivery are described. Relevant Irish legislation is included in this chapter where appropriate.

Chapter three describes the methodology used in the study. This chapter details how the research was conducted. The approach used to gather the data is outlined and the rationale for choosing this approach. It deals with population and sampling, sourcing the sample, sample size, pilot study, data collection and data analysis. Finally it looks at the ethical considerations involved in carrying out the research.

Chapter four presents the findings and the discussion. The findings are presented under two main headings: “The impact on families of caring for a child with an Intellectual Disability” and “supports and services available to parents”. These themes are discussed and related back to the literature.

Chapter five gives an overall conclusion to the research and makes recommendations arising from it. This chapter also includes suggestions for future research.

2 Chapter two: Literature review

2.1 Introduction

This literature review explores the relevant published literature relating to parents experiences of rearing a child with an Intellectual Disability. It also explores supports available to the family and the family's experience of the use of respite care. Government legislation and policies relevant to this area will also be referred to where appropriate. The models of care (including the medical and social models), family adaptation and support structures available to families to assist in the caring for Intellectually Disabled children will also be described. The different forms of respite care are also described. Some demographic information in relation to the number of people in Ireland with a disability will also be presented. The chapter will start with a description of the evolution of understanding and treatment of people with an Intellectual Disability.

2.2 The evolution in understanding of Intellectual Disability

Inclusion Ireland (2009) state that Intellectual Disability is one of the most common disabilities within society. In Ireland, the Department of Health and Children use the phrase 'Intellectual Disability' and describe the condition as involving, a greater than average difficulty in learning. According to Inclusion Ireland (2009) a person is considered to have an intellectual disability when the following factors are present: general intellectual functioning is significantly below average; significant deficits exist in adaptive skills; and the condition is present from childhood eighteen years or less. Braddock & Parish (2002) suggest that disability is how society views the impairment of others. The way in which society viewed Intellectual Disability went through dramatic changes over the centuries. Our understanding of Intellectual Disability has grown and expanded from one of ignorance and fear to one of knowledge, understanding and acceptance. With this understanding our care for people with Intellectual Disabilities has also evolved. In 1981 Payne & Patton stated that there has

been significant development in the approaches used in the care of people with these difficulties. But it hasn't always been this way.

James (2005) said that during the Middle Ages in England people with an Intellectual Disability were referred to as “idiots” derived from the Latin word, “idiotic”, to mean an ignorant person and the Greek word, “idiots”, which meant unfit for public life. Syzmanski & Wilska (1997) suggest that individuals with disabilities were thought to have no opinions or incentive with regard to their own functioning. Syzmanski & Wilska (1997) also state that during the middle ages people with an Intellectual Disability were seen as a consequence of their parents' sinful behaviours. Miles (2001) states, that during the reformation in Europe, Martin Luther claimed that people with disabilities were the workings of the devil. Edward (1971) says that in 1866 an Idiot Asylum was established on Randall's Island, New York. An Idiot school opened up shortly afterwards. Edwards also goes on say that the titles and philosophy of these institutions were a reflection of the ignorance and lack of understanding prevalent in the 1900s. According to Radford (1991) this lack of understanding of Intellectual Disabilities and their causes carried over well into the 20th century. Berkson (2004) says that this uninformed way of thinking was still present in Ireland right up until the early part of this century.

Despite the lack of understanding of Intellectual Disability as described above there was also evidence of positive change in understanding going back as far as the 18th century. Winzer (1993) states that in France, towards the end of the 18th century Phillipe Pinel's idea of “moral management” facilitated a development of social awareness towards individuals with Intellectual Disability by endorsing humane care, education and recreation rather than the previous approach of forcing compliance. Winzer (1993) tells how a German student of Pinel's, Edouard Seguin, built on Pinel's studies and further advocated the educational system as well as physical therapies to improve the skills of such individuals. By the mid-19th century Seguin's aspirations reached the United States of America. There, he himself, along with some physicians, founded the first school for individuals with Intellectual Disabilities called the American Institutions for the Feeble Minded, Winzer (1993). However, even as progress was being made it is evident from the title of the school above that people with Intellectual Disabilities were still labelled in a negative and diminishing way.

According to Scheerenberger (1983) in 1905 in France, Binet & Theodore in an effort to treat people as an individual was to group children with special educational needs according to their abilities. They did this by the application of the first usable intelligence test (known today as an IQ test). However, Scheerenberger (1983) states that the Eugenics movement and Social Darwinism occurred around the same time and these ideologies proposed that Intellectual Disability was inherited and weakened the human species. Brockley (1999) describes how protective care and safety of the community from such people was promoted. They were considered to be a menace to society because criminality, drug abuse and antisocial behaviour were associated with Intellectual Disabilities. Brockley (1999) says that this viewpoint continued on until the 1920s when a growing emphasis on community care and integration into communities started to be advocated and this is the perspective to this day. Kaiser (1999) states the civil rights movement also prompted parents to advocate for social integration for their children with Intellectual Disabilities.

Radford & Park (2003) state that in the early 1970s one of the most outstanding impacts on modern history was the evolution in understanding of Intellectual Disabilities and in particular the principle of Normalisation which was introduced by Wolfenberger in 1972. Until the 1970s care for people with Intellectual Disabilities occurred in institutional settings. In North America Wolfensberger (1972) suggested the concept of Normalisation through which he advocated the acceptance of an individual's disability and advocated that services and living conditions should be available in the same way to the person with the disability as to the non-disabled person. This disability movement formed a perspective allowing people with Intellectual Disabilities to be cared under, not just a medical model, but a social model as well. In today's society these two forms of care are intertwined yet also stand alone. According to Braddock & Parish (2002) the medical model was the sole model used to care for people with an Intellectual Disability during the early 1900s. This model saw them housed in an institutionalised setting with little or no individual care. This has now changed and a more holistic approach to the care of people with Intellectual Disabilities is becoming the norm. In the next section a more detailed look at the medical and socials model of care is described.

2.3 Medical model of disability

Crow (2010) states the basic idea of the medical model of disability is that a person's functional limitation or impairments are the base cause of any disadvantages experienced and these disadvantages can therefore only be corrected by treatment or cure. According to the medical model of care, Intellectual Disability is considered a problem of the individual that is caused directly by a disease, or an injury at birth, or some other health condition. Mitra (2005) suggests that medical intervention is needed for such differences and takes the form of treatment and rehabilitation rather than care. In the medical model, individuals with impairments are considered disabled, and "impairment" is the term used for their condition, irrespective of whether or not they experience limitations in their daily life. Yeo & Moore (2003) suggest that the medical model of disability has generally included a charitable dimension. This can be seen through the involvement of religious orders in almost all aspects of the disability sector. The medical model considers disability as a health and welfare issue and welfare institutions as conduits for interventions. Coleridge (1993) suggests the disabled are seen as largely incapacitated, unable to sufficiently help themselves and hence are seen as needy. Yeo & Moore (2003) state that interventions focus on the incapacity of individuals to perform functions due to their physical or emotional nature, the causes of which may be war and violence, poverty, failure of medical devices, unhealthy lifestyles, accidents or environmental considerations. Shakespeare (2002) noted little attention is given to what the Intellectually Disabled can offer themselves and the larger society in which they live in. For this reason Shakespeare (2002) says that the medical model of disability is considered patronising. Yeo & Moore (2003) suggest the medical model may also be the basis for exclusion of the disabled. They also go on to say that the exclusion and segregation of the Intellectually Disabled encouraged organisations to design patronising welfare programmes as well as ways to cure the afflicted in the hope that their afflictions would be eradicated permanently. Hand-outs and free treatment to the afflicted were what these welfare programmes were mainly geared to as they saw this as the only form of intervention. Wills (2000) suggests the medical model was developed on the theory that disabled people were hated or feared due to their conditions and the responsibility rested on the non-disabled or religious orders to provide treatment and care in order to create an aspect of normality in the lives of

people with an Intellectual Disability. Smart (2002) said the downside to such an approach is that interventions were designed and provided by people who did not know what it really felt like to be disabled.

Branfield (1998) says people with disabilities seldom had any say in the shaping of the interventions that affected their lives. Branfield (1998) also goes on to say that in later years a different model emerged where the needs of the individual were taken into account. This model is known as the social model of care. In time the social model took precedence over the medical model. The social model of care was concerned with the individual as a unique person in his or her own right. In the next section a more detailed examination of the social model is given.

2.4 Social model of disability

Paley (2002) suggests that the social model is a movement away from the medical model that viewed the person with a disability in a mechanistic way as something to be fixed. He described the social model as,

“The social model of disability is a reaction to the dominant medical model of disability which in itself is a Cartesian functional analysis of the body as a machine to be fixed in order to conform to normative values” (p.189).

In contrast to this medical model Paley (2002) states that the social model of disability identifies general barriers, negative attitudes and segregation by society either purposely or inadvertently whereby society disables the individual more than the individual themselves. Paley (2002) also suggests while sensory, intellectual, physical or psychological differences may be the cause of a person's functional limitation or impairment; these do not have to lead to a disability unless society excludes people because of their individual differences. The beginning of the social model can be traced back to the 1960s Paley (2002). However, according to Michael & Sapey (2006) the actual specific term, the Social Model, emerged from the United Kingdom in the 1980s. In 1983, the disabled academic Mike Oliver coined the phrase "Social Model of

Disability" in reference to these ideological developments that focused on uniqueness and looked to the person's abilities rather than to his/her disabilities. Mike Oliver actually highlighted the model in the public domain. Oliver (1990) argued that the biggest problem for people with disabilities lies within society itself. He said that there are numerous social and physical barriers which inhibit people who live with a disability. Among these are access to employment, reduced financial aid, lack of physical amenities and that the barriers are not in the individual disability itself.

In response to some of these issues in an Irish context the government in 2005 passed the Disability Act into Law. This act provides legal protection for people with a disability. This Act incorporates a number of elements. For example, the Act establishes a basis for an independent assessment of individual needs, a related service statement and independent redress and enforcement for persons with disabilities. In other words people with disabilities have a right to proper assessment of need, adequate services tailored to their needs and a mechanism for redress if necessary. The Act also stimulates that public bodies have an obligation to be pro-active in employing people with disabilities. The Act also puts a restriction on information from genetic testing that can be used for employment, mortgage and insurances purpose. The Disability Act (2005) is part of a framework of Government legislative measures which support social inclusion. Other essential elements in the Government legislative framework are, The Employment Equality Acts (1998-2004), The Equal Status Act (2000), The Education for Persons with Special Educational Needs Act (2004), The Comhairle (Amendment) Bill (2004). The Employment Equality Acts for example, outlaw discrimination in a wide range of employment and employment related areas. One of the areas is the area of disability which covers physical, intellectual, learning, cognitive, emotional and a range of medical disabilities. In other words a person cannot be treated unfairly on the basis of any of the disabilities if that person fulfils the requirements for a job. Another important piece of legislation introduced by the government is the Education for Persons with Special Educational Needs Act (2004). This Act makes provision for the education of people with special educational needs, to provide that education wherever possible, in an inclusive environment with those who do not have such needs. The National Council for Special Education (NCSE), to assist schools to plan and deliver support services were established in 2003. This council works with parents, schools and other interested parties to ensure all children with disabilities have an opportunity to go to main stream

school. All these initiatives are indicative of progression in Ireland in relation to the understanding of people with disabilities and also are positive steps towards inclusion and equality for all people.

Foster (2008) states that the social model of Intellectual Disability suggests that attempts to change or cure individuals especially when it is against the wishes of the individual can be seen as discriminatory and prejudiced. Wanting to change or cure people (which may be seen as originating from the medical model) can damage the self-confidence and socially exclude people who are constantly subjected to it. Finn (2009) states that sign language in the deaf community is a valuable resource allowing individuals the ability to communicate. However, parents of deaf infants argue against cochlear implants due to their child's inability to consent to them and they prefer to wait until the child is old enough to make decisions for him/herself. In other words these parents are taking the views of the child into consideration and are giving the child a voice in his/her own life. Seidel (2004) stated that people diagnosed with an Autism Spectrum Disorder (ASD) may argue against efforts to change them to be more like others. Instead Goodley (2001) suggests that people with autism argue instead for acceptance of diversity and for accommodation to their different requirements and goals. In a similar vein Seidal (2004) makes the point that some people diagnosed with a mental disorder also argue that they are just different and don't necessarily need to conform to the expected norms of society.

Engel (1977) proposed the idea of a Biopsychic Social Model of disease or disability as an all-inclusive attempt by physicians to address the need to accept diversity. The Biopsychic Social Model is a general model or approach (which is a combination of both medical and social models of care) that suggests that biological, psychological and social factors all play an important role in human functioning in the background of disease or illness. The model suggests that health is better understood in terms of a combination of biological, psychological and social factors rather than purely in biological terms. Link & Phalen (2001) suggest the present social model mirrors these ideas as it provides care in a non-medical capacity, integrating individuals into communities, encouraging their own unique qualities, strengths and abilities and allowing them to partake in community living without the stigma associated with an Intellectual Disability, while at the same time their medical needs are also being met.

In summary, over the years understanding of people with an Intellectual Disability has gradually moved from one of fear to one of enlightenment and acceptance. In the approach to care, a move has been made from an exclusively medical approach to a more social/holistic one. When the medical and social models of care are combined (such as in the Biopsychic Social Model) a complete care package can be made available for the individual. Frankel, Quill & McDaniel (2003) say that this Biopsychic Social Model systematically considers biological, psychological and social factors and their complex interactions in understanding health, illness and health care delivery.

Having examined models of care in the next section the personal experience of caring for a son or daughter with an Intellectual Disability will be examined. The impact of providing care to a child with complex needs can have a significant impact on parents in terms of stress, caregiving, marital relationship difficulties, financial problems and family dynamics. These stresses will be examined next. Some demographic information is presented first to put into context the number of people in Ireland with a disability and the number of families in Ireland caring for a loved one with a disability.

2.5 Demographics

In the Republic of Ireland, the most recent census was carried out in April 2011. It found a total of 595,335 individuals, which accounted for 13 per cent of the population of Ireland, have some form of a disability. These disabilities include Intellectual Disability, mobility problems, blindness, psychological or emotional conditions. Of these 289,728 individuals or 48.7 per cent are male while 305,607 individuals or 51.3 per cent are female. Based on the overall numbers of people with a disability, less than 10 per cent are in their twenties, rates increase steadily for persons in their forties and fifties to reach over 20 per cent by age sixty. From age seventy on rates increase more sharply for both males and females with 75.1 per cent of all females aged 85 and over having a disability.

Census 2011, showed that 57,709 people or 1.3 per cent of the population have an Disability. The greatest incidence in this group was amongst ten to fourteen year old males, with almost 4000 registered in this age group. In the same age group there were

1900 registered with an Intellectual Disability. More than four out of five individuals or 81.3 per cent of those with an Intellectual Disability were also registered as having a second disability. The most common of which was a difficulty with learning, remembering or concentrating which was indicated by 40,550 people or 70.3 per cent of the people with an Intellectual Disability. One in three or 19,329 individuals also indicated a psychological disability along with an Intellectual Disability. The most common difficulty experienced by those with an Intellectual Disability was with working, attending school or college which affected 57.2 per cent or 33,001 individuals. Among children from birth to fourteen with a disability, 99 per cent of individuals were living in a private household. Almost all children with an Intellectual Disability are living at home. A child with an Intellectual Disability needs more care and attention generally than a non-disabled child. In the next section the impact of caring for a child with an Intellectual Disability will be explored.

2.6 The impact of caregiving

Olsson & Hwang (2006) suggested that caring for an Intellectually Disabled child can affect the lives of parents and siblings and is often linked with stress, particularly in mothers, as they are the main caregivers. In 2007 Kenney & McGilloway carried out a study in Ireland examining the quality of life of Irish families caring for a child with an Intellectual Disability. Highlighting the quality of life of Irish family's and parent carers. This found that that the Irish parent/family carers were stressed due to the nature of the caring role and also as a lack of support from disability services. The study also found that some carers had developed medical and/or psychological problems as a result of their fulltime caring duties. The study also highlighted families faced financial challenges as a result of reduced income because of the extra time needed in caring duties. Kenney & McGilloway (2007) also reported that the parents/carers also reported positive gains as a result of caring for the child with an Intellectual Disability such as growing as a person, learning new skills and becoming more determined to face challenges.

Emerson & Hatton (2007) say that children with an Intellectual Disability have significant problems with cognitive and adaptive functioning, increased mental health problems with greater rates of severe sleep disorders. Richdale, Francis, Gavidia-Payne & Cotton (2000) also state that Intellectually Disabled children may also have challenging behaviours and physical health problems. According to Simonoff, Pickles, Chandler, Loucas & Baird (2008) many Intellectually Disabled children need greater levels of care and more educational supports than children who are non-disabled. Fidler, Hepburn & Rogers (2006) suggest that parents who provide care for their Intellectually Disabled child are more likely themselves to experience mental health problems and stress than parents who have non-disabled children. According to Barron, McConkey & Mulvany (2006) in the Republic of Ireland and Northern Ireland, over 12,500 people with Intellectual Disabilities are living with family carers, 50 per cent of whom live with both parents and 30 per cent with one parent family and the remainder living with other relatives. It is therefore important that these families get all the support they need to remain healthy and to provide a high standard of care to their children. McConkey (2005) suggested that a child who is more physically dependent on the parent results in the parent struggling to provide care for the child with the parent's ability to continue in the caring role reducing over time. Hartrey & Wells (2003) also report that the impact of caring for an Intellectually Disabled child is multidimensional and includes financial, social and practical aspects of the lives of families.

According to Simonoff, Pickles, Gringras & Chadwic (2007) the realisation that your child has an Intellectual Disability can be difficult, especially when the child has significant intellectual impairment. In relation to this Quire & Rutter (1994) suggest that this means that the timing and process of diagnosis is all important as sometimes the diagnosis may be delayed until the individual is in his/her teens or has reached adulthood. Scottish Intercollegiate Guidelines Network (2008) say that in these instances the family will have gone through immense stress and because of lack of a clear diagnosis may not have adequate access to necessary services. Hamilton (2006) suggests that the outcome of this delay can result in the support needs of the child not being met. According to Gaudiano & Herbert (2006) these delays in services have been found to be one of the main issues linked to stress and unhappiness for parents of children with an Intellectual Disability. Gaudiano & Herbert (2006) go on to say further delays in the identification and delivery of relevant interventions may have an adverse

impact on the child's learning ability, adaptive skills and communication skills. Goodman & Linn (2003) suggest that the effect of this can result in individuals failing to understand the child's difficulties and behaviours. They also state where diagnosis is delayed the family has no formal support to meet the needs associated with caring for a child with an Intellectual Disability. Makela, Birch, Friedman and Marr (2009) say without diagnosis families have no clear direction in terms of care or interventions for the Intellectually Disabled child which must be very challenging.

Keenan, Dillenburg, Doherty, Byrne & Gallagher (2010) state the needs of families who parent a child with an Intellectual Disability in the early years are mainly concerned with diagnosis. Llewellyn & McConnell (2005) states that for parental caregivers to a child with an Intellectual Disability collaboration with the primary care team initially begins following the birth and diagnosis of a child with an Intellectual Disability. He also states that this can be an emotional time for parents, with feelings of sorrow and sadness for their child. However, they must still maintain their role as a parent. The initial reaction of parents is to provide care for their Intellectually Disabled child at home. In the United Kingdom a service support group, Family Support (2011) suggest that there is a growing concern that the information sought by families on the supply, demand and quality of childcare, and the availability of childcare for children with disabilities in particular is growing. The Carers Association in Ireland (2012) also have seen a rise in demand for information and feels that this searching for information may indicate that there is a growing need for extra services for the disabled child. McCallion & McCarron (2007) say that in Ireland, the concern raised regarding availability of services is matched by the growing concern about a rapid increase in an ageing population, especially with regard to ageing parents of an Intellectually Disabled child. In line with this Keenan (2007) says that planning for the future care needs of the child is important. Dillenburg & McKerr (2010) states that parents who have cared for their Intellectually Disabled child who are now themselves becoming older are concerned with issues like poverty, the child's lack of skills, social exclusion and the future for their child, once they are no longer able to care for them.

According to Lecavalier, Leone & Wiltz (2006) providing care for an Intellectually Disabled child with high support needs leaves parents drained emotionally and physically. Jeon, Brodathy & Chesterson (2005) suggest parents who provide care to an

individual with an Intellectual Disability may experience loneliness, frustration and lack of understanding from others. Providing care for an Intellectually Disabled child can have a deteriorating effect on the health and wellbeing of all family members and it is important that both the needs of the family members and the Intellectually Disabled child are met equally according to Chan & Sigafoos (2000). MacDonald & Callery (2004) state that all families are uniquely different yet they still need individual and practical support on various levels and the availability of such supports provides an invaluable service to families. Hartrey & Wells (2003) noted that families require services that are comprehensive, accessible and available in an emergency situation. They added that with these services the challenges faced by families are lessened and families can get the time to regroup.

Crowe & Florez (2006) found that when likened with mothers of non-disabled children, mothers of disabled children spent considerably more time involved in childcare activities and significantly less time in leisurely activities. Jeon, Brodathy & Chesterson (2005) in a similar fashion found that caring for a child with an Intellectual Disability with high support needs leaves parents exhausted emotionally and physically. According to Jeon et al (2005) carers may also experience cycles of anxiety, frustration, loneliness, stress and burnout.

Beresford (1994) found that in a marital or cohabiting relationship a partner is likely to be the most intimate person in an individual's life. He also suggested that knowing each other thoroughly is a support when dealing with a disabled child. He also suggested that mothers and fathers maybe affected differently by childhood disability and have different needs related to coping with the disability. Hastings (2005) found that in comparison to fathers, mothers of children with Intellectual Disabilities have shown increased symptoms of depression, increased caregiver burden and increased stress. In comparing the responses of mothers and fathers to caregiving in families of children with and without a Developmental Disability Oelofsen & Richardson (2006) discovered that mothers with children with a Development Disability showed increased stress, a weaker sense of rationality, and poorer health compared to their husbands while the contrasting group (parents of children without Developmental Disabilities) experienced little or no mother/father variances. In smaller studies examining the impact of caring

for a child with an Intellectual Disability Keller & Honig (2004) did not find significant differences between mothers and fathers on measures of stress, on family support, family harmony, marital change or the quality of life within the family. Wang Summers, Little, Turnbull, Poston & Mannan (2006) suggest that the lack of significant information and findings in these smaller studies suggests that differences between mothers and fathers may be minimal.

In an effort to understand better, the impact on fathers and on mothers Wang et al (2006) found that for fathers, acceptance of the child with the Intellectual Disability and harmony within the family was a factor in reduced stress. While mothers were also affected by harmony within the family, lower socio-economic status and greater care demands predicted more stress. According to Kumari Gupta & Harpreet (2010) mothers of children with Intellectual Disabilities specifically showed higher stress and lower health scores on measures of overall functioning.

Though few studies have been carried out on the marital satisfaction of parents of children who have been diagnosed with an Intellectual Disabilities there are a few cautious findings Doran (1999). Myers & Johnson (2007) state that in addition to all the above mentioned stress, parents of children diagnosed with autism spectrum disorder may face the added difficulty of trying to find time for both their children and their partners which can cause added strain on the couple's relationship. Brobst, Clopton & Hendrick (2009) says that some couples have reported disagreeing about the child who has been diagnosed with autism, resulting in the father avoiding coming home. Brobst et al (2009) suggest disagreements can lead to lower relationship contentment in couples of Intellectually Disabled children compared to parents of non-disabled children. O'Neil & Burke (1983) state that it is important to realise that there is often conflicting research findings. Some studies find differences in contentment between families with and without an Intellectually Disabled child. More research in this area would be beneficial.

According to Baxter, Cummins & Yioltis (2000) having an Intellectual Disability child puts stress and strain on the family and causes a shift in family dynamics. Parents often respond to these demands in different ways. Gallagher, Phillips, Oliver and Carroll (2008) say for the mother extra caregiving and little leisure time can cause stress and mental health problems. According to Dyson (1997) the father can often respond in

different ways to these extra pressures. The next section will specifically look at the impact on the father.

2.7 Paternal contribution to caring

Lamb & Tamis-LeMonda (2004) suggest that the father's involvement in the care of the Intellectually Disabled child has slowly increased over the past several decades. However, Riggs (2005) says that the mother's level of caregiving is still greater than that of the father. The Social Care Institute for Excellence, United Kingdom (SCIE) (2005) suggests that the father's needs often go unseen by professionals leaving him feeling un-nurtured. Fathers have been acknowledged by researchers in this field as being 'hard to reach' McConkey (1994) p.4 and 'the invisible parent' Ballard (1994) p.293. Pleck (1997) and Lamb et al (2004) state that a rise in the father's participation is usually a positive benefit to all family members.

Lamb et al (2004) say that in particular mothers of the Intellectually Disabled child benefit when the father assumes responsibility for the child care as this allows the mothers more time to engage in preferred activities and reduces their stress levels. According to Esdaile & Greenwood (2003) mothers also appear to enjoy their children more and are more satisfied with their marital relationships when fathers become more involved in the child rearing.

More involvement from the father also greatly benefits the child. Pleck & Masciadrelli (2004) found the enhancement of academic learning and social-emotional wellbeing when the fathers were more involved with the child. They also found that the father's involvement had a positive effect on the outcomes of all their children. Such outcomes included improved relationships with their peers, less behavioural problems and greater self-esteem. In line with this Brotherson & Dollahite (1997) also say fathers of children with disabilities may be especially involved in playing with their children, nurturing them, disciplining them and deciding on the use of services that they may need. Kazura (2000) says that how the father spends time caring for the child is different to that of the mother. The mothers take on more of a caring role with the fathers spending more time in play or fun activities with the child. According to Paquette (2004) this offers a setting

for fathers to take part in the child's development through play, especially rough and tumble play. West (2000) on the other hand says that fathers as a whole can have varied experiences of fatherhood and of their child's Intellectual Disability. This is reinforced by Lamb & Billings (1997) who said fathers of children with disabilities often report feelings of guilt, disappointment, lack of control, inferiority and isolation, which can lower their overall sense of well-being. Ferrari (1986) also describe fathers of children with disabilities as often reporting feeling cut off from sources of social support, and many report feeling resentful toward others (e.g., neighbours, co-workers) who fail to offer such support.

It isn't just parents who are impacted by a child with an Intellectual Disability, siblings are also. The next section will examine the impact on siblings

2.8 Sibling adjustment

According to Morris, Silk, Steinberg, Myers & Robinson (2007), sibling relationships are the longest relationships any person will be involved in. They state that this relationship can be unsettled when a sibling is born with an Intellectual Disability.

Doppelt, Pilowsky, Yirmiya, Gross-Tsur & Shalev (2004) outlined the changes that occur when a sibling is born with an Intellectual Disability within the family. He states that a sibling with an Intellectual Disability may result in increased levels of stress for the non-disabled siblings and this can have erratic effects on their psychological well-being. According to Doppelt et al (2004) following the birth or diagnosis of an Intellectually Disabled sibling, the non-disabled sibling may have to manage with changes in the family unit, such as structure and activities, have feelings of guilt and shame, loss of their parents' attention and more episodes of parental stress. Abrams (2009) reviewed the different ways in which siblings of Intellectually Disabled children are affected and what can be done to ensure positive impact. He found that the non-disabled children have feelings of shame, have extra caregiving duties and feel the lack of parental attention. He went on to say that non-disabled siblings may isolate themselves from their Intellectually Disabled sibling or they may become overly

protective caretakers and they may mature and become independent before their time. They may feel guilt and may feel that they are less important in their parents' eyes. Abrams (2009) also states that the non-disabled sibling can become neglected by the mental health and health care systems. To avert negative adjustment outcomes and to encourage positive sibling relationships, Abrams (2009) recommends giving the non-disabled sibling a voice in the care of the Intellectually Disabled sibling and giving support if needed such support maybe the opportunity to share experiences, worries, and concerns with other children in similar circumstances in an understanding and non-threatening environment. Abrams (2009) suggests this may help to develop greater self-esteem and ways of dealing with problem situations as they arise.

Modry & Mandell (2007) state siblings' relationships with their Intellectually Disabled siblings are important in helping the disabled child's social, emotional and socio-cognitive development. According to Karos & Howe (2007) siblings influence each other's development by providing support to each other. He describes this support as providing "a frequent source of companionship, play, help and emotional support" (p. 578)

According to Berk (2001) when the Intellectually Disabled child is around eight months old siblings of the child normally tend to spend more time together and the Intellectually Disabled infant can find comfort in their presence during the absence of a parent.

Howe & Recchia (2009) note that while the quality of sibling relationships decreases and conflicts increase in the adolescence years, the opposite happens as adolescent siblings mature and gain social skills. Strohm (2002) says that siblings of Intellectually Disabled children are usually expected to mature sooner than their peers, as they need to care for themselves, while their parents provide care for the Intellectually Disabled sibling. Strohm (2002) also suggests that the child will also be expected to provide care for the Intellectually Disabled sibling. Strohm (2002) also states that with this added responsibility the non-disabled child will feel valued and useful, adding to their sense of acceptance of the disabled sibling. However, McAuley & Layte (2012) say that this may also interfere with their social development and ability to establish independence.

According to Seligman (1991) female siblings are more likely to be expected to provide caregiving than male siblings. He also states that the siblings of Intellectually Disabled children realise that the responsibility of caring goes beyond supporting the mental wellbeing of the child and must include the physical wellbeing of the child. He also goes on to say that siblings blame themselves for being unable to stop the deterioration in health that their sibling can sometimes experience this can leave the siblings feeling upset, helpless and distressed. Greenberg, Seltzer, Hong & Orsmond (2007) say that a lot of siblings provide daily assistance in the form of household chores, transport, caregiving duties and emotional support. Landeen, Whelton, Dermer, Cardamone & Munroe-Blum (1992) found that siblings of an Intellectually Disabled child had concerns regarding the disabled child's future, which related to leisure and social activities, the future of the child's illness, their future medical needs and the future resources available. Meyer & Vadasy (2001) suggest that siblings who have grown up with an Intellectually Disabled child may have a greater level of understanding and development than peers of a similar age. They go on to say that these siblings show greater leadership skills in the area of understanding and awareness. According to Jacobs & McDermott (1989) siblings may also experience financial hardship due to the financial burden of the necessary care of their Intellectually Disabled sibling. Burke (2004) suggests that an excellent source of support for siblings of an Intellectually Disabled child can be to share their experiences with others who understand first-hand what it is like to have a disabled sibling. Siblings like parents are impacted by the Intellectually Disabled child. Hastings (2007) suggests that the siblings support the disabled child but also may require extra support themselves

Meyer & Vadasy (2000) in their study found that a number of siblings highlighted that being apart from their disabled sibling for a period of time allowed them time to recharge and provided a much needed break. Dykens (2006) maintains that older female siblings, who are not disabled, are normally expected to provide more care giving duties to a brother or sister with an Intellectual Disability.

Apart from emotional and time demands arising from caring for the Intellectually Disabled child there are also financial implications to having a child in the family with an Intellectual Disability Golics, Basra, Finlay & Salek (2013). The next section now goes on to describe this.

2.9 Financial challenges

Olsson & Hwang (2006) state the stress and burden related to caring for an Intellectually Disabled child impacts on the parents' mental health. Reichman, Corman & Noonan (2008) say that part of this stress arises from the economic burden of raising a child with an Intellectual Disability can be very taxing. Greenberg & Floyd (2010) says that this economic burden has a specific impact on mothers. They go on to say that parents with and without children who have an Intellectual Disability have highlighted that mothers of children with disabilities work less paid hours, which results in a lower income than mothers of non-Intellectually Disabled children. In a another study Kelly, Craig, McConkey & Mannan (2009) found that parents of Intellectually disabled children have financial difficulties as a direct result of reduced income due to extra time required in caring for their child.

According to Ricci & Hodapp (2003) financial hardship as a consequence of having to work less hours in order to provide care affect mothers more than fathers, especially where the fathers do not take on an active caring role. The same can be found from increased workload due to the unusual cycle of childcare relating to an Intellectually Disabled child (e.g. more direct supervision, more washing and more sleepless nights). Warfield (2005) notes that mothers report spending longer caregiving hours with the child with the Intellectual Disability than the fathers and this resulted in an increased absenteeism from the mothers' employment.

The Social Policy Research in York in the United Kingdom (2007) suggests that carers of Intellectually Disabled people have great difficulty in carrying out their role as caregivers due to the high levels of stress and financial burden involved, This Social Policy Research group reported that the additional financial burdens of caring for an Intellectually Disabled child was estimated to be double that of caring for a non-disabled child Todd & Shearn (1996) also noted that additional costs associated with the bringing up of an Intellectually Disabled child could not be confined solely to the early years of caregiving. Over the lifespan, parents and carers of people with Intellectual Disabilities will meet a number of unforeseen circumstances and financial challenges that require new skills and coping mechanisms Grant, Ramcharan, McGrath, Nolan &

Keady (1998). Shearn & Todd (1997) also suggests that an additional burden for carers of people with Intellectual Disabilities is the fact that their employment levels are greatly reduced.

Shearn & Todd (2000) presented the viewpoints of mothers of children with Intellectual Disabilities with respect to their employment. Mothers who took part in the study faced unusual time difficulties, such as having to attend medical appointments, sporadic behavioural difficulties with their child, which only they could deal with and this led them to believe that their employment prospects were limited by social attitudes towards parents of children with Intellectual Disabilities. These social attitudes may be perceived as other employees being disgruntled as a result of parents of an Intellectually Disabled child taking a lot of time off work to attend medical appointments according to Leonard, Brust & Sapienza (1992). Todd & Shearn (1996) state that while employment can have a positive effect on the caregiver, that unless active support is given, the psychological pressure of the double role of caregiver/employee can be very substantial. Shearn & Todd (2000) also state that the lack of opportunities for employment for caregivers lead to feelings of isolation and abandonment. They additionally state that problems with gaining employment can cause social restrictions that worsen the pressures of caregiving. Evans (2004) says one aspect of caring for a child with an Intellectual Disability that can impact on employment is when the child has challenging behaviour. This will be examined in the next section

2.10 Behaviors that challenge

Becker (2004) noted that it was in the educational sector that attention was first given to challenging behaviour. Emerson (1998) described challenging behaviours as any behaviour that was intense, frequent and had a lasting duration and which could put the physical safety of a person in danger. Emerson (1995) suggested that challenging behaviours can have a lasting impact on the life of the individual displaying the behaviour and can also present difficulties for the carers.

According to Farmer & Aman (2010) challenging behaviours are symptoms of a variety of Developmental Disabilities. Cheng & Chen (2009) also suggest one of the most common Developmental Disabilities is Autism Spectrum Disorder (ASD). Rojahn, Matson, Mahan, Fodstad, Knight & Sevin (2009) go on to say that it is categorised by a shortfall in social skills, adaptive functioning and communication, which when present further aggravate challenging behaviours. According to Emerson, Kieran & Alborz (2001) challenging behaviours occurs in ten to fifteen per cent of individuals with an Intellectual Disability with an increased occurrence between the ages of fifteen to twenty four, with the majority of the behaviours being displayed by males. The characteristics displayed include aggression, destructive behaviour and self-injury. Hastings (2002) explained that children who have Intellectual Disabilities and display severe challenging behaviour can cause major disruption within a family unit, Grey, Pollard, McClean, MacAuley & Hastings (2010) go on to say that this may result in maternal ill health, family breakdown, depression and isolation. Gibson (1995) suggests caregiving for an individual with an Intellectual Disability is a highly individual process and evidence suggests that some families may never adjust fully to this process. Paczkowski & Baker (2007) go on to say that dealing with an Intellectual Disability within the family unit can be a powerful source of stress in parents' lives. When the person with the Intellectual Disability displays challenging behaviours then the stress levels in the family tend to increase dramatically according to Hastings (2002).

Emerson (2005) states that a person with an Intellectual Disability who displays challenging behaviour will find that this is a primary impediment to independence; to integration into a community setting and how others view them. Maslach (2003) also says these knock on effects will of course cause more family distress. Ben-Sasson, Cermak, Orsmond, Tager-Flusberg, Carter, Kadlec & Dunn (2007) found that parents can also be troubled by the child's unpredictable behaviour as a result of sensory problems, such as the fascination with some objects and the avoidance of other objects, inconsistent responses to stimulation and vulnerability to sensory overload. Duhig, Renk, Epstein & Phares (2000) noted that mothers overall tend to describe children with behavioural problems as more difficult to parent and to manage than fathers do. Hauser-Cram, Warfield, Shonkoff & Krauss (2001) found that some fathers were less affected than mothers in terms of stress related to the role as caregiving parent to a child with

challenging behaviour. Cummins & McMaster (2006) suggest that to have a child with an Intellectual Disability who engages in difficult to manage behaviours places further burdens on an already stressed family.

Having looked at some of the challenges and stresses on families who have a child with an Intellectual Disability the next section will look at skills and competencies that parents bring to the caring role.

2.11 Parental proficiency

Heaton, Noyes, Sloper & Shah (2005) state that in addition to the need for information regarding their child's Intellectual Disability parents also want to know what skills they may require in order to help their child. They also stated that the skills required of parents will vary depending on the child's needs. Mansell & Wilson (2010) say depending on the extent of a child's needs the parents may need training in the use of one or more specialised pieces of equipment. Heaton et al (2005) noted that when parents succeed in mastering the use of equipment, they are then left to get on with it, but in this study the parents thought some level of continuing support would be of benefit. Gibson (1995) highlighted that training is an essential part in providing care for example, in the administration of emergency medication. He also stated that most parents readily accepted that their Intellectually Disabled child needed essential equipment, but also recognised that this equipment may place restrictions on their children's educational and social activities and family outings may have to be planned around the child's specific equipment. Heaton et al (2005) noted that parents with an Intellectually Disabled child who are heavily reliant on technological equipment for independence also found that this limited the choice of employment opportunities for parents to take up. Roberts & Lawton (2001) noted that parents of Intellectually Disabled children saw themselves as professionals in the area of their own child's Intellectual Disability Roberts & Lawton (2001) go on to say these parents often had to explain their child's condition to the health professionals which was a source of worry to them. Clavering, Goodley & McLaughlin (2007) found that these parents felt that their concerns about their child's health were not always investigated as thoroughly as they would have liked having a child with an Intellectual Disability can put pressure on

families in many different areas. These pressures can be felt at a financial level, marital level and mental health level. On top of these pressures parents have also to find time to learn how to use equipment and at the same time continue to care and parent all children in the family. With so many demands on parents, it is essential that supports are available to them. These supports can be at voluntary or statutory level. These family supports are examined in the next section as well as how these supports are delivered.

2.12 Support structures

This section will examine the support structures parents' access to enable them to provide care for their child with the Intellectual Disability. It will also explore the assistance given by extended family and friends. Respite care is seen as a valuable resource for all parents when it is available. This section will review its delivery and accessibility and the views of the parents. The different models of respite care are also described. In order to look at these supports it is important to examine the need for them. This is done with regard to the statistics on disability available from the Irish Census 2011.

2.13 Extended family

According to Brown, Anand, Fung, Isaacs & Baum (2003) parents of Intellectual Disabled children often rely on extended family members to provide care and support for a child with an Intellectual Disability. Pal, Das, Chaudhury & Sengupta (2005) state that parents of children with Intellectual Disabilities, especially mothers, reported getting practical help from extended family members, mainly in the area of child care responsibilities. The grandparents of an Intellectual Disabled child also play an important role in supporting the parents. According to Hornby & Ashworth (1994) a study of parents of children with Intellectual Disabilities found that grandparents, predominantly maternal grandparents, aided with childcare and assisted with transport for their grandchild. Harris, Handleman & Palmer (1985) conducted a study including parents and grandparents of nineteen families with a child with autism. This study found that maternal grandmothers had more empathy than the paternal grandparents for their

daughters' problems in raising their grandchild. Harris et al (1985) suggest that maternal grandmothers provided more support when raising an Intellectually Disabled grandchild than all of the other grandparents. This was a benefit to their daughter as it relieved maternal stress levels. However, McCallion, Janicki, Grant-Griffin & Kolomer (2000) say as the child becomes older it becomes too much of a responsibility for the grandparents to provide a caring role. This may be because grandparents, for example, are themselves getting older or because carers do not want to "put others out" MacDonald & Callery (2004).

However, Brown et al (2003) found that a lot of parents said that the quantity of support they receive from extended family members was not sufficient to help them in effectively managing their child's Intellectual Disability. Brown et al (2003) also state that parents of children with an Intellectual Disability report that although they receive emotional support from extended family members they do not receive adequate practical support. Brown et al (2003) suggested that this lack of practical support by extended family members may be related to a lack of knowledge and understanding of the child's disability and also a feeling of being uncomfortable around the child. He also hypothesised that an absence of involvement from extended family members may be associated with geographical barriers. Brown et al (2003) also goes on to say other factors such as disagreements regarding treatment, emotional differences between family members and internal family disputes may explain the absence of support to parents of children with Intellectual Disabilities from extended family members. Hillman (2007) suggests that after reviewing studies of grandparents of children with Intellectual Disabilities that additional stresses can be experienced as the parents of the children may disagree with the grandparents over management of the child's care and in disciplinary matters.

In the United Kingdom, a service support group for parents who have a child with an Intellectual Disability, The Working Together with Parents Network (2009) suggest that different generations have different ideas on the best ways to bring up and look after children. They say that for parents of children with Intellectual Disabilities, coping with different views on raising a child and resisting even well-meant suggestions that they should do things differently is likely to be particularly hard. Crnic, Low & Christine (2002) also suggest that stress levels among parents of an Intellectually Disabled child

are related to increased emotional difficulties that arise between extended families. According to Woolfson (2004) these emotional difficulties can be caused by guilty feelings on both sides in relation to caregiving duties. Finnegan, Dooley & Noonan-Walsh (2004) go on to say sometimes more formalised care can be more helpful to the family and that this can come from a state body which specialises in the short term care of individuals with an Intellectual Disability. Freedman & Boyer (2000) say that the support comes in the form of short respite breaks designed to allow the caregivers' time to recuperate and use it as a support for them. This lessens the burden of care and any feelings of guilt away from the caregivers. According to Hornby (1994) care delivered in this way gives the parents a break and relieves guilt that may arise when extended family are involved in the caregiving. The next section will give an account of respite care and the different forms it which it is delivered.

2.14 Respite care

In relation to the need for respite care In Ireland, The Annual Report of the National Intellectual Disability Database Committee (2011) found that in the fifteen year period between 1996 and 2011 there was considerable growth in the number of residential support places that were utilised in Ireland. The number of people availing of these services rose dramatically from 871 in 1996, to 2,647 in 2001 and to 4,242 individuals in 2006. From 1996 to 2011 4,963 individuals availed of overnight respite. This was a total increase of 469.8 per cent. Even with this rapid increase in the number of respite placements Chadwick, Mannan, McConkey, O'Brien, Finlay, Lawlor, & Harrington (2013) state that families in Ireland still remain the main providers of support for people with Intellectual disabilities. Although respite care for Intellectually Disabled children has developed and grown over the last three decades in Ireland, MacDonald, Fitzsimons & Noonan-Walsh (2007) state that in spite of increased availability services in Ireland still lack sufficient resources to fully meet the levels of demand.

Respite care can be defined in many ways. The National Disability Authority of Ireland (2004) defines respite care as,

“Temporary Residential care, based either in a centre or community based, that is intended to support the upkeep of people with disabilities in their own homes. This temporary care can cover a crisis period, take place on a periodic basis to enable a caregiver to have a break, or it can provide the person with a disability with medical, therapeutic or support services” (P.212).

Cotterill, Hayes, Flynn & Sloper (1997) suggested that respite care was originally set up to allow people with an Intellectual Disability to remain at home by allowing their caregivers a break from the duty and stress of full-time caring. According to Chesson & Westwood (2004) the fundamental basis for respite care is that caregivers who benefit from this service in the short term are more likely to continue to care for their family member fulltime in the long term. Cotterill et al (1997) states that respite care allows family members to stay together longer, whilst providing care for their loved one and allowing for the postponement of a permanent residential placement. Savage (2002) says that caregivers within the family are always positive about respite care. They utilise and value the short breaks for different reasons. According to Pollock, Law, King & Rosenbaum (2001) parents said that they valued services which were flexible, readily available and ones which provided a high quality of care. Pollock et al (2001) also found that parents favoured respite care that was regular, short in duration and services which were local as these were least unsettling to the child with the Intellectual Disability and also family and parents were able to monitor service quality. Finnegan, et al (2004) goes on to say that there is a need for a lot more services for children with an Intellectual Disability.

Matthiessen, Avdagovska, Mardhani-Bayne and Price (2009) found caregiving is a demanding job and no one person is equipped to do it alone. Respite care provides short-term breaks that can relieve stress, restore energy and promote balance in life. Seeking support and maintaining your own health is a key to managing your role as a caregiver. Despite these positives Hartrey & Wells (2003) say parents may also feel guilty and discontent having placed their child in a respite care facility. According to Gallagher et al (2008) parents may also feel that they are alone and nobody understands their circumstances or can care for the child like they do.

2.15 Forms of respite care

Mac Donald & Callery (2004) suggest that respite care involves many different steps in supporting parents and that respite needs to be planned and have purpose and be understood by the involved parties. It may comprise of a carer providing care for a short period of time within the child's home, either with the parents remaining in the home or alternatively when the parents are not present. They also state that another method of care involves the child leaving the family home for a short period in order to receive care in the provider's home or at a service provider's facility. Finally, they state that there are specialist facilities to cater for an Intellectually Disabled child's needs such as nursing facilities or children's hospices which may entail an overnight stay or a placement for several days. In Ireland, carers reported that whilst they valued a short break service they were not satisfied with the frequency of provision, with a main issue being lack of short breaks during the summer holidays say Wilkie & Barr (2008). Merriman & Canavan (2007) report that what families need is a range of flexible options from which they can choose the best option for them. According to the Multiple Sclerosis Society in Ireland (2009) many low-income families find additional costs, such as travelling to and from the respite centre a barrier to accessing residential respite care. Regrettably, according to Paulin, Claesson & Brodin (2001) parents also point out that they have to fight for the assistance from, and control over, support services. Stronger and more tenacious parents receive more resources and more control. Paulin et al (2001) go on to say that this results in parents who battle for more respite time inevitably taking respite time off parents who don't voice their opinion. This results in the less vocal parents being deprived of much needed respite.

The modern day care facility is staffed with health care workers and registered Intellectual Disability nurses. They are employed to provide a quality of care for children and adults who have an Intellectual Disability. According to Clough, Bullock & Ward (2006) high support facilities offer specialist care for children and adults with severe Intellectual Disability needs which are compounded by very challenging behaviour. Clough et al (2006) suggest the duty of these homes is to provide good quality care and assistance for service users who have to live away from home, for a short period, maybe during a family crisis or following an episode of difficult

behaviour. McConkey, Kelly, Mannan & Craig (2010) say that children with a profound level of Intellectual Disability require a higher level of care due to challenging behaviours that they may display. They also found that families in this situation used respite on a more frequent basis. The provision of quality services for people with an Intellectual Disability has evolved through the years from one where the person with the disability wasn't seen as an individual with unique needs to a service where each person has an individualised care plan. Person centred planning (PCP) has an essential part to play in ensuring self-determination for the lives of people with intellectual disability. It is typically taken as an indicator to the quality of services and it is regarded as especially important when considering its effectiveness in impacting on the lives of people with Intellectual Disability. Robertson, Emerson, Hatton, Elliot, McIntosh, Swift, Krinjen-Kemp, Towers, Romeo, Knapp, Sanderson, Routledge, Oakes & Joyce (2005) six indices of PCP which are efficacy of social networks, community involvement, scheduled day services, contact with friends, contact with family and choice are regarded as a standard measure. PCP is a central part of the package of care offered in respite centres for children with Intellectual Disabilities.

According to McConkey et al (2004) short break (respite) services are regularly provided as a support to families but little attention has been paid to adjusting these services when children and families have complex needs. For the child with complex needs respite care can take place within the family home or in a specialised facility. It comprises of a professional providing care in the child's own home, usually for a few hours including an overnight stay. Short breaks like this can allow parents to attend to their own social needs giving them an opportunity to relax and recharge. Regular or shared care provision is usually either in the region of two or three days per week, every weekend or alternate weekends according to Barron et al (2006). This method of care may come from family support or from a residential care facility. Another form of respite care is placing the child with a host family is discussed below. This service is provided by the Health Service Executive (HSE).

2.16 Host family

In relation to respite care in another family's home Merriman & Canavan (2007) described this in the following way:

“Respite care in another family's home is a growing source of respite care. It differs from the other formal out-of-home settings in a number of ways. Most significantly, the family setting mirrors the service user's usual surroundings and offers the potential for building relationships in the community” (p.13).

Hanrahan (2005) described this type of respite care in a similar way. He said it involved care for the child with the Intellectual Disability in another person's home for a short time. It involves enlisting families from the local community who have the skills to help and matching them to the people with the disabilities. This form of care is a way of including a person with Intellectual Disability into a community setting. It links the person to another family or individual carer who is specially recruited and prepared for this purpose. Host families can then provide breaks which vary from one day visits to overnight stays and can include annual holidays depending on the situation. Kelleher's (2001) report in St Michaels' House Dublin states some of the specific advantages of family based respite are that the individuals who use the service can benefit from one to one attention where there is consistency in caregiving and routine and there are no staff or people changes. In this way relationships are built between the host and the guest and also between both families. Deal (2006) found mixing with children of a similar age for example, can increase the social network of the person with the Intellectual Disability. McConkey et al (2004) say family based respite can be more flexible than residential placements, especially in times of crisis, as individuals can adjust their schedules quicker. They are also less expensive than professionally staffed institutional care centres.

According to Robertson, Hatton, Emerson, Wells, Collins, Langer and Welch (2010) family based respite benefits the person immensely. Residential Care with a host family can offer short and long term accommodation, care and support to children or adults with an Intellectual Disability in a family setting. It can be part time, three or four days

a week or it can be full time, seven days a week. This model provides a viable support service for children or adults with mild, moderate, severe or profound Intellectual Disability and provides an alternative to the current traditional respite type care settings. Walsh (1983) found overall, host family service provision gives the person with an Intellectual Disability an opportunity to participate in the community setting and offers their family a break from the routine of giving continual care and at the same time gives the family of the child with the Intellectual Disability breathing space. This type of respite is been gradually introduced by the Brothers of Charity in Galway.

2.17 Service funding

Respite services are funded by the Health Service Executive (HSE) and guided by HSE standards of care. These services are free of charge if the family meet the relevant criteria such as a need for respite care. The Irish government also assists the caregiver/parent through grants and allowances. One such grant is Domiciliary Care Allowance (DCA). This is a monthly payment for a child aged under 16 with a severe disability and who requires ongoing care and attention. This care must be substantially over and above the care and attention usually required by a child of the same age. The child is likely to require full-time care and attention for at least 12 months. There are no PRSI conditions and it is not means tested. The DCA scheme is a statutory scheme with the primary legislation provided for in the Social Welfare and Pensions Act 2008. This grant can be used by parents to pay a qualified person or a family friend to care for their Intellectual Disabled child at home or outside of the home. It is at the discretion of the parents as to how they use this grant. At the age of sixteen a child with an Intellectual Disability can receive a disability allowance. This is not payable to a person who is considered to be in full-time residential care. In 2009 the Department of Health initiated a Value for Money Report and Policy Review of the Disability Services in Ireland. The report was published in 2012. The focus of the report is an evaluation of the efficiency and effectiveness of disability services in Ireland, wholly or partly funded by the HSE, encompassing both the statutory and the voluntary sectors and a review of current policy in relation to the disability sector. The report makes 117 recommendations. The primary purpose of the report was to assess how well current services for people with disabilities meet their objectives, to support future planning and to develop services and

make recommendations. The priority recommendations of the Report are: to strengthen the national disability function, to shift the focus of the disability services from a predominantly group based service approach to one that is person centred, to develop a national resource allocation model that will provide a framework for individualised budgeting and that “money follows the patient”. From this report it can be seen that it is the person with the disability, with his or her own individual needs or care plan that will shape service delivery.

The majority of Intellectual Disability services are privately owned or still governed by religious orders, who work side by side with the HSE to deliver a standard of care for individuals with an Intellectual Disability. Along with these religious orders there are numerous other service providers both public and private, for example, the National Learning Network provides a range of flexible training courses and support services for people who need specialist support job seekers, unemployed, people with an illness or disability. Nua Health Care provides services for people with Asperger Syndrome / High functioning Autism. Rehab Care group is an independent international group of charities and commercial companies which provides training, employment, health and social care, and commercial services, all of which are specifically tailored to meet the needs of the person with the Intellectual Disability providing training, day services and accommodation. A lot of care is now provided by persons qualified at Fetac Level 5 (Further Education and Training Awards Council of Ireland), which is a minimum standard of education is required to work with individuals with such specific needs. Fetec Level 5 is awarded by the Quality and Qualifications of Ireland body (QQI). Despite the fact that we have moved forward in terms of how we think of service provision, the actual qualification required now to work in this field is lower than it was in decades past.

Barron et al (2006) state that, family care arrangements have received relatively little attention within government policy making, and hence service provision has been largely reactive and unregulated. Since 2013 respite services which are made up of a variety of residential homes and recreation facilities are all subject to quality assurance from the Health Information and Quality Authority (HIQA) of Ireland. HIQA is an independent authority which was established to monitor the quality of health and social care services delivered in Ireland (public, private and voluntary). HIQA was established

as part of the Government's Health Service Reform Programme, which was established in May 2007 to drive continuous improvement in Ireland's health and social care services. Inspection of respite care facilities fall under its remit since 2013.

Services now are staffed with qualified personnel. However, the current minimum qualification to work in the disability sector is below the professional training and qualifications required to work in other health care areas. It is a challenge faced by the disability sector to employ personnel who are employed to at least a level seven degree since the minimum requirement is a FETEC level 5. For example, the HSE in Sligo are recruiting health care workers at a minimum standard FETEC level 5 to work in the Intellectual Disability area of HSE Cregg services. .

The census 2011 has shown us that the majority parents choose to care for their Intellectually Disabled child at home. In the older medical model of service delivery people with an Intellectual Disability were cared for in institutions. This, despite its disadvantages did relieve families of the stress of caregiving, but resulted in less individual care for the person with the Intellectual Disability. In today's social model of care individuals with an Intellectual Disability enjoy family life and integrate into main stream society. The families adapt their homes and lives to care for their Intellectually Disabled child. Redmond, Bowen & Richardson (2000) says despite all the positives of this care in the home it can also bring challenges to the parents and the family unit. These challenges emerge on many levels. There is extra time needed to care for the child with the disability. Routines need to be re-arranged; stress and financial strains need to be managed. According to Chesson & Westwood (2004) for families to continue to care for the Intellectually Disabled child at home supports such as respite care are invaluable. Respite gives the child and the family a break. The family gets time to engage in activities that would be otherwise difficult to do.

2.18 Conclusion

In conclusion, this literature review has given an account of the evolution of our understanding of Intellectual Disability. It has also presented information on the impact

on families of caring for a child with an Intellectual Disability. It has also looked at respite care and its contribution to the care of the child with the Intellectual Disability.

Two major themes that emerged from the review were the following: The demands that are placed on all the family in caring for a child with an Intellectual Disability and the parents' experience of the use of respite care.

The literature indicated that the challenges parents faced had different impacts on mothers than on fathers. Mothers, for example often felt stressed and isolated whereas fathers coped by staying away from home. These demands and challenges on the family came from different sources. When the child was non-verbal this placed greater stress on the coping reserves of the parents. When the child had complex medical needs this also created great strain. Stress also arose from financial pressures. Stress in the literature was also linked to isolation. This isolation arose from the time spent in caring for the child and hence less free time for the parent him/herself. Another aspect of this theme was the stress experienced by siblings and the shame and blame that siblings felt. The literature also stressed the positive aspect for siblings in terms of their leadership skills and their maturity and independence.

The literature in relation to respite care indicated that it was a valuable resource for parents. Respite was seen by parents in a positive light and helped give the parents space for themselves and the rest of the family. However, literature from the Irish context indicated that the amount of respite care available was inadequate to meet the growing demands for this service from parents.

Having reviewed the literature the next chapter will describe the methodology employed to carry out this research.

3 Chapter three: Methodology

3.1 Introduction

In this chapter the research methodology used to gather the necessary data to fulfil the aims of the study will be described. The overall aim of the study was to explore the experiences of parents whose Intellectually Disabled child lives at home and to explore the parent's experience of using respite care. The research approach, design, sample, methods of data collection, data analysis and ethical considerations will all be described. The rationale for the chosen method will be discussed. The chapter will be presented in a logical order reflective of the recognised steps in the research process.

As a young male, in my early thirties, working within the Intellectual Disability sector, frontline exposure to persons with Intellectual Disability and their families occurs on a daily basis. I have worked in various area of Intellectual Disability over the last decade which includes fulltime residential community settings for children, respite services for children and I have also worked with adults. I have also worked in high support facilities, semi-independent and independent living facilities. Throughout my years of working in this sector I have helped individuals transition from fulltime residential living to living in the community. I have worked with children and adults with different types of Intellectual Disabilities such as Autism, Robinson syndrome, Down syndrome and many others both diagnosed and undiagnosed. Each individual I worked with had unique traits and each and every person has a unique personality and also their needs were very different and individual. I have gained immense experience over the years working within this sector, through training, working with colleagues, dealing with challenging situations and through learning about the different types of disabilities. The driving force behind my research has been my experience of working in this sector and also the lack of knowledge and published research on parent's experiences of rearing a child with an Intellectual Disability. Over the years I have met many parents who avail of fulltime residential care and periods of respite care and I was interested to get a better understanding of their experiences of using this service. In order to gain a personal insight into the lives of families caring for a child with an Intellectual Disability I chose to use the qualitative research approach. This allowed me to get a unique insight into the

very personal experience of parents in relation to rearing their child with the Intellectual Disability. Each parent's journey in this caregiving role is different and the qualitative approach allowed the researcher to capture this uniqueness. The fears, the challenges, the anxieties, the supports and the joys associated with this caregiving role was recounted by the parents in a safe and contained environment in a face to face interview with the researcher. This interview format created an environment where delicate and complex information could be gathered in a sensitive interactive manner. The parents were able to describe their unique lived experiences. Burns & Grove (2005) suggested that qualitative research would gather rich, in-depth knowledge and insight into human experiences, perceptions and behaviour. Silverman (2006) similarly stated that the qualitative approach will generate data which provides a true insight into people's lives. I believe in using the qualitative approach I gained this true insight into the lives of the people interviewed.

3.2 Research approach

There are two main approaches to research, quantitative and qualitative. The approach the researcher will adopt depends on the nature of the topic under investigation and the type of data required meeting the aims and objectives of the study. Quantitative research is a formal, objective, systematic process used to obtain quantifiable, numerical and measurable information Burns & Grove (2005). According to Bryman (2004) quantitative research is based on the methodologies of positivism and neo-positivism. Positivism is an epistemological position that advocates the application of the methods of rational sciences to the study of social reality. In a critique of quantitative research Bryman (2004) suggests that it gives a false sense of precision and accuracy. He also states that it impedes the connection between research and everyday life through a reliance on instruments and procedures and that the analysis of relationships between variables creates a sense of a static social world separate from the lives of people.

On the other hand qualitative research differs from this more traditional quantitative approach. Parahoo (2006) describes qualitative research as a subjective, flexible, interactive and systematic approach used to explore human experience, perceptions,

motivations, intentions and behaviours. According to Bowling (1997) the strength of this approach is to study people in their natural social setting and to collect naturally occurring data. Donalek & Soldwisch (2004) state that qualitative research is inductive in its approach moving from the perspective of the individual or group to possible wider themes where there is little known about the topic. This inductive approach gives the researcher an opportunity to develop knowledge and understanding of the topic under investigation and to gradually gain expertise in the area being studied. Sarantakos (1998) suggests that qualitative research attempts to capture reality as seen and experienced by the respondent. It tries to study reality without any pre-conceived ideas Sarantakos (1998). Qualitative research at its most simple can take the form of observation. In observation, the researcher simply observes the research matter in the way a child psychologist may watch a child play. Bowling (1997) stated that the obvious advantages of qualitative research over quantitative research is revealed in situations in which there is little existing knowledge and where the issues are sensitive and complex. Despite its strengths Sarantakos (1998) suggests there are limitations. It is time consuming, its reliability may be compromised due to the researcher's subjectivity and ethical issues may also occur, Sarantakos (1998). Qualitative research particularly suits the current study due to the sensitive nature of interviewing parents about their experiences of caring for a child with an Intellectual Disability. Sarantakos (1998) suggests that quantitative research seeks to understand people by using procedures that allow the respondents to share their views and experiences and that the researched and the researcher are seen as two equally important elements of the same situation. In this research semi-structured interviews were used to gather data which gave the respondents freedom to express their views and also gave the researcher a guide to follow.

3.3 Population and sampling

According to Polit & Beck (2010) the population refers to the entire group of individuals who meet the specified criteria for a given study to be carried out. Cormack (2000) defines a sample as a sub-section of the population who are selected to participate in the study. There are two main sampling strategies, specifically probability and non-probability sampling. According to Tashakkori & Teddlie (2003) probability

sampling techniques are primarily used in quantitatively oriented studies and involve selecting a relatively large number of units from a population or from specific subgroups (strata) of a population, in a random manner where the probability of inclusion for every member of the population is determinable, whereas non probability sampling involves identifying a specific range of units close to the subject to be sampled, this form of sampling cannot be used to generalise the whole population. There are different methods used in non-probability sampling such as grounded theory and purposeful sampling. Purposeful sampling was used in this study. Parahoo (2006) says that purposive sampling is especially represented through the key informant technique wherein one or a few individuals are asked to act as guides to a culture. In the case of this study the key informants were parents who cared for an Intellectually Disabled child and availed of respite care. Key informants are observant, reflective members of the community of interest who know much about the culture and are both able and willing to share their knowledge, according to Bernard (2002). Patten (1990) p134 describes this approach well when he, states that the logic and power of purposeful sampling lies in selecting information-rich cases for in-depth study. Purposeful sampling was utilised in this study as the researcher wished to capture the intimate experiences of parents who care for a child with an Intellectual Disability.

According to Morse & Field (1996) there are two main principles that guide the choice of who to include in a study, namely appropriateness and adequacy. Appropriateness refers to the identification of participants who can best express their experiences according to the goals of the study. Adequacy refers to collecting data until a rich description is attained and data saturation is complete. I believe I have met these principles in this piece of research. Appropriateness was achieved because all the parents who took part in this study meet the study criteria; namely, they had a child with Intellectual Disability and they also availed of respite services for the child. Adequacy was achieved through the use of semi-structured, in-depth interviews that allowed the researcher to continue to gather information until enough data was gathered to adequately describe parents' experiences of rearing a child with an Intellectual Disability and parents' experience of using respite care

3.4 Sourcing the study sample

At the start of the study access to potential participants was sought by the researcher by writing to the managers of two respite care centres, four principals of main stream schools and two of special needs schools (Appendix 1). One of the respite care centres was located in the north west of Co Sligo and one in Co. Leitrim. These centres offered respite care to children with an Intellectual Disability who lived at home, in this study the definition of a child is taken from the Child Care Act 1991 which states that,

“A child is defined as “a person under the age of 18 years, excluding a person who is or has been married”

The Sligo respite care centre was purpose built with six beds. The Leitrim respite care centre was in an existing Intellectually Disabled residential centre consisting of four beds. Both respite services were staffed by Intellectual Disability nurses with supporting care staff with a Fetec Level 5 qualification in healthcare. All of the schools contacted were within Sligo town and borough.

The letter sent to the managers of these centres outlined the research proposal and it asked if it were possible to identify possible interviewees for the study. No response was returned from the respite facility in Leitrim. A follow up phone call was made. A message was left on voicemail but no further contact was received from the centre. Therefore this centre was not included in the study. The Sligo Respite Centre responded via a telephone call and agreed to take part in the study.

The researcher wrote to the Principals (Appendix 1) of four main stream schools with special needs classes and two dedicated special needs schools. One of the principals of a dedicated special needs school from North Sligo contacted the researcher initially by telephone to agree to take part in the study. None of the principals of the other five schools responded. After trying to contact these five principals by phone only one from one of the main stream schools was contactable but this principal declined to take part in the study. Following this a letter was then sent to the principal of the special needs school who had agreed to take part in the study and the manager of the respite centre in Sligo who had agreed to partake. The letter included information to be forwarded to

potential participants. This information included a letter outlining the researcher's intentions for the study including how the rights of the participants would be upheld, a consent form to agree to partake in the study and to agree to be audio recorded throughout the interview (Appendix 2). A stamped addressed envelope, addressed to the researcher to return the relevant documentation was also included.

The principal from the special needs school who agreed to partake in the study got consent from the parents' committee to send a letter to the parents who had a child with an Intellectual Disability enrolled in the school. The researcher had no part in this process due to the confidential nature of the request. After obtaining consent from the parent's committee the principal sent thirty six letters with an information pack (as described above) to parents whose child with an Intellectual Disability was attending the special needs school. The manager of the respite centre in Sligo sent fourteen letters with an information pack, to parents whose child with an Intellectual Disability attended the respite centre. Out of the initial fifty letters distributed by the respite care centre Sligo and the principle of the special needs school, thirteen parents responded. Of the thirteen, ten were parents whose children attended the special needs school and three were from parents whose children availed of the respite centre. This was a written response through the stamped addressed envelope provided in the information pack. On confirmation of permission to contact the thirteen parents, the researcher contacted the participants via telephone to introduce himself and discuss the study. Ten finally agreed to participate in the study. In a period of six weeks, they returned all of the documentation, signed permission slips and the signed agreement to have the interview audio recorded.

3.5 Sample size

In general, the sample size in qualitative studies tends to be small. According to Holloway & Wheeler (2010) in qualitative studies sampling consists of a small number of participants studied in-depth. In qualitative research the number of participants to include is often not specified at the beginning of a study and information is collected until data saturation is achieved Kvale (1996). Bowen (2008) says data saturation

involves the continuation of sampling until repetition of the data set has occurred and no new information is emerging.

Thirteen parents' fitting the inclusion criteria were contacted to participate in this study. Although small, the sample size provided the researcher with the opportunity to fully explore the parents' experiences. Of the thirteen parents who initially consented to the study, ten proceeded with the research. These ten parents comprised the sample. The inclusion criteria necessary for this study were:

- A parent of a child between the ages of one to eighteen with an Intellectual Disability
- The child must reside in the family home, but also avail of a respite placement.
- Parent's had to understand the aims of the study and the consent mechanism and also participate voluntarily.

3.6 Pilots study

Bell (1996) suggests that the purpose of a pilot study is to get the bugs out of the questions, so as the main study will flow smoothly. The researcher interviewed one parent within his/her own home to determine whether the questions asked were understandable, appropriate and produced the information required to meet the research aims. This pilot interview went well, but some changes were required to the interview format. The researcher felt that adequate and relevant information was gathered using the semi-structured questioning format. The interview conducted for the pilot study met the defined aims and objectives of the research and was included as part of the study.

3.7 Method of data collection

According to Burns & Grove (2005) data collection involves a lengthy process and commences once ethical approval and access to participants is obtained. Data collection is the process of selecting participants and gathering information from these subjects. In qualitative research, methods of data collection are less structured and more flexible

than those in quantitative research. Qualitative research can include several data collection methods, mainly interviews, focus groups, videos, documents and observations. According to Corbin & Strauss (2008) the researcher can use one or several of these sources.

For the purpose of this study, interviews were selected as the method of data collection as they are uniquely sensitive and powerful methods of capturing the lived experiences of family according to Kvale (2007). There are three types of interview formats differing in degrees of structure, namely structured, semi-structured and unstructured. Semi-structured interviews were carefully chosen for this study as they provided the researcher with some structure and control over the interview process. Polit & Beck (2010) say that although semi-structured interviews are focused they also give participants the freedom to respond in their own words, provide as much detail as they wish and offer explanations when necessary.

An interview guide was developed that focused on the topics to be covered when collecting the data. This guide was developed through researching the relevant literature as documented in the literature review. The literature review resulted in the identification of a number of themes and these themes informed the research process and the design of the data collection method i.e. the semi-structured interview. The decision of use a semi-structured data collection mechanism was to facilitate the respondents in ways in which a structured questionnaire could not. This method was chosen to maximise the input of the respondents and to capture as many valid, relevant and insightful perspectives from the respondents as possible. According to Holloway & Wheeler (2010) with semi-structured interviews, the sequencing of questions is not the same for every participant and there is flexibility in the phrasing and order of the questions. This facilitated the gathering of the data in this piece of research.

3.8 Location of study

The participants gave written consent to be contacted by telephone to inform them of the content of the interview. They had given signed consent for this (Appendix 2). Nine participants wished for the interviews to be carried out within their home. The location

of one interview had to be changed at short notice when the home could not be used as planned and a small private function room in a nearby hotel was organised. Polit & Beck (2010) note the importance of a quiet setting free from distractions when conducting interviews and this was achieved in this study. Nine of the parents felt comfortable being interviewed in their own home, whilst one travelled to meet in a nearby hotel where a private room was booked. Once the location was organised a date and time suitable to the participants was selected to conduct the interviews.

Polit & Beck (2010) state that researchers who conduct qualitative research must to an even greater extent than quantitative researchers, gain and maintain a high level of trust with participants. Polit & Beck (2010) emphasise that data collection is an intense and exhausting experience especially when the subject matter being studied concerns stressful life events. The establishment of trust with the participant is paramount. In the case of this study before the interviews commenced the researcher introduced himself. He then reiterated the rights of the participants allowing them the opportunity to withdraw from the study should they feel uncomfortable with the content. After this he asked the participants a number of demographic questions and began to establish a rapport and trust. The researcher then began to follow the semi structured interview format. Within this semi structured format (Appendix 3) six main questions were asked. Each question was an open ended question which resulted in the participant covering several topics related to the question. There were a number of sub-questions for each main question to prompt the researcher if the participant did not initially divulge the information themselves. Appropriate questions were asked so as to develop the information required for the study. The researcher allowed the participants to communicate openly without interruptions and facilitated this process by listening attentively, only intervening to probe as appropriate to get more detail information. Probing questions were used in a way to encourage participants to elaborate on important information. The researcher listened carefully to the words of each participant and provided support without becoming emotionally involved and compromising the ability to collect data objectively. With this in mind the interviews were conducted in a non-judgemental way and the researcher was respectful of the experiences of the parents as they described caring for a child with an Intellectual Disability.

The participants were aware that they could pause or terminate the interview at any time if they become tired or felt emotional. All ten parents interviewed completed the interview. Each interview took up to one hour. A further hour was left between each of the interviews to enable the researcher time to reflect and prepare for the subsequent interviews. Not all interviews were carried out on the same day. This allowed the researcher time to think about each interview conducted and to familiarise himself with the main themes and concerns arising. The time frame allocated to complete all interviews was a four to five month period from October 2012 to February 2013.

3.9 Data analysis

A thematic analysis approach was used in analysing the findings of this research. Polit & Beck (2010) states the purpose of qualitative data analysis is to organise, provide structure and get meaning from research data. Data analysis is a difficult and time consuming process requiring the researcher to constantly move between the stages in the analysis process until a complete and comprehensive understanding of the subject is achieved.

Braun and Clark (2006) outline six phases used in thematic analysis. These phases are:

- Familiarisation with the data
- The generation of codes from the raw data
- The identification of themes from among the codes
- A review of the themes
- Defining and naming themes
- And reporting on the themes

This process was used in the analysis of the information gathered from the semi-structured interviews.

All of the interviews were audio recorded live while the interviews were taking place. Familiarisation with the data occurred initially transcribing all the data in word

documents, one for each participant. The audio recordings were listened to numerous times and the transcribed interviews were read and reread,

In the next phase of the analysis codes were generated from the raw data. For example, in response to the question as to how the parents spent time with friends it became evident that they didn't spend time with them. This question generated data that indicated that the parents saw the caring role as a twenty four job that their friends had drifted away from them. This information was coded as "being isolated". This code also emerged when the parents were asked did the use of respite allow them to meet other families in similar circumstances. In response to this question the parents indicated that they had no contact with the other families but would welcome such contact as a source of support. Using this procedure numerous codes were generated. Other codes were concerns about the other siblings, stress experienced by the mothers in particular, concerns regarding financial needs. Codes also emerged that indicated benefits to the family for caring for a child with an Intellectual Disability. These were that the child was the life of the house, that the family couldn't imagine life without this child and also that there was a positive impact on siblings in terms of maturity and independence.

These codes were then combined into an overall theme of the impact on the family of caring for a child with an Intellectual Disability.

The second major theme arose in the same way. Three main codes were identified that fed into the theme relating to the experiences of respite care. These were the benefits to parents of respite care, the lack of knowledge among parents of what occurred during respite and issues around the availability and delivery of the service.

It is significant to point out that even though the data analysis process as described above seemed to flow from one stage to the other, the researcher actually worked forwards and backwards between the units, the themes and the database until comprehensive themes were established.

3.10 Ethical considerations

The focus of the research is on the family life of parents of children with an intellectual Disability and their use of respite care. Although it was parents who were interviewed, the researcher is aware that the information sought concerned children. For the purpose of this study the child as stated before is,

“A person under the age of 18 years, excluding a person who is or has been married” Department of Children and Youth Affairs (2015)

Although the researcher was not directly involved in interviewing children, the researcher is acutely aware of the broader debate around the ethics concerning assent in children as part of a study, even if not directly involved. An article in the Australian Ethical Research Involving Children (2013) by United Nations International Children's Emergency Fund (UNICEF) Office of Research has highlighted this current debate around interviewing children, but as yet there are no ethical guidelines applicable or available in regards to this.

It is the researcher's responsibility to obtain ethical approval before commencing a research study so as to safeguard the rights of the participants. A letter seeking ethical approval and a copy of the research proposal was submitted to the local ethics committee in Sligo Institute of Technology. The principal of the special needs school also got approval from the parents committee to contact the parents to enquire if they were willing to take part in the research. The manager of the respite centre followed the centre's own internal procedures.

Bulmer (1982) stated that the scientific community has responsibilities not only to the ideals of the pursuit of the objective truth, but also to the subjects themselves. He states that the researcher must always take into account the effects of his work and act in such a manner so as to preserve the rights and integrity of the subjects as human beings. According to Parahoo (2006) there are ethical implications at every stage of the research process. It is the responsibility of the researcher to attain ethical approval prior to starting a research study in order to safeguard the rights of the participants. This was

achieved in this study by having the interviewees complete a consent form which included details of their ethical rights, their right to privacy, their right to withdraw from the study at any stage and full confidentiality.

Parahoo (2006) outlined the ethical principles which should be considered when conducting any research involving human subjects. These principles include the right to self-determination and the right to privacy, anonymity and confidentiality, the right not to be harmed and the right to full disclosure

The right to self-determination: In order for consent to be obtained by the researcher to proceed with the study, the participants were initially contacted by third parties who were the principals and managers of respite centres. This contact was in the form of a letter, which briefly outlined the research objectives for the study and how their participation would be of great benefit (Appendix 2). This allowed the participants' time to decide voluntarily whether or not to participate in the study. Attached with this letter (Appendix 2) was a consent form with a stamped envelope addressed to the researcher. The consent form was to get permission from the parents to take part in the study and also to allow the interviews to be audio recorded. All participants were treated fairly and equally and all were given the time to express themselves as they wished in the interviews without interruption.

In relation to the right to privacy, anonymity and confidentiality Parahoo (2006) states that the principle of confidentiality refers to respecting the information gathered from and about the participants. Information gathered through the data collection process was securely stored in a password protected computer. The identity of the participants was protected by assigning each participant a code and any identifying information was omitted from the study. In addition, data was stored and managed in accordance with the Data Protection Act (2003).

In relation to the right not to be harmed the researcher made sure that the research study caused no harm by notifying the participants that they could pause or terminate the interview at any time if they required a rest or a moment to themselves or if they became emotionally distressed.

In relation to the right to full disclosure the participants were informed both verbally and in writing of all aspects of the study including the potential risks and benefits. The right of the participants to withdraw from the study at any time without reason was explained to the participants. All participants were provided with the opportunity to question or to seek clarification about the research. All of the participants were content with the information provided to them.

3.11 Study limitations

The study was limited in a number of ways.

Firstly it was very difficult to access a larger sample of participants. This was due to a number of reasons. Five of the six schools contacted and one of the two respite centres contacted declined to take part in the study. This may have been due to the sensitive nature of the study. As well as a small sample was limited to a very small geographic area.

Secondly the study was limited in the composition of the sample. Nine mothers and one father participated. The information gathered therefore, didn't give adequate voice to the experiences of fathers.

Thirdly the study was limited because it was unable to separate or explore if there are different experiences related to rearing a younger child with an Intellectual Disability as opposed to rearing an older child with an Intellectual Disability. The small sample size made this impossible.

This chapter has detailed the qualitative methodology which the researcher used to explore the experiences of parents of a child with an Intellectual Disability who lives at home but who also uses respite care. The next chapter presents and discusses the findings.

4 Chapter Four: Findings and Discussion

4.1 Introduction

The aims of this qualitative study were to look at the experiences of parents who care for an Intellectually Disabled Child and to examine their experiences of using respite care. The study was conducted over a four month period in the west of Sligo, Donegal and Leitrim between the months of October 2012 to February 2013. The sample consisted of ten parents who gave consent to be part of the study. Nine of the interviewees were mothers and one was a father. The age range of the mothers was forth two to fifty two years and the father was thirty six years old. Each family had one child with an Intellectual Disability. Four children had Autism Spectrum Disorder, two had Cerebral Palsy, one had Rett Syndrome and the remaining three had no official diagnosis. There were seven boys aged between six and twelve years and three girls aged between fifteen and seventeen years. Six of the children attended special needs schools, three attended special needs classes in a main stream school and one child remained at home due to medical reasons. The parents were interviewed and the researcher had no contact with the children. The data was analysed using a thematic approach.

Two broad themes emerged from the research. These were the impact on the family of caring for a child with an Intellectual Disability and supports and services available to parents (grandparents, respite care). In presenting the findings and discussion the respondents are referred to as P1, P2, and so on to P10 who is the male respondent. The theme “Impact on the family of caring for a child with an Intellectual Disability” will be presented first. This broad theme was composed of the following elements: The impact on the parents, the impact on the marital relationship, Isolation experienced amongst parents, Challenging behaviours, Structural changes to the house, Financial impacts, Concerns for the child’s future, The impact on siblings. The second theme “Supports and services available to parents” will be discussed and presented under the following headings: Grandparents, A form of support, Concerns about availing of respite, Issues with service delivery, Parental knowledge and involvement with the service.

4.2 The impact on the family of caring for a child with an Intellectual Disability

4.2.1 Impact on parents

Parents deal with an Intellectual Disability child differently. Fathers need a firm idea of the further needs and abilities of the child while the mother focuses on the caring and nurturing duties according to Hastings et al (2005). Mothers tend to have a greater influence over their child's day to day caring needs than fathers. Hastings et al (2005) found that most mothers saw the disabled child as a permanent baby despite the child's age and always felt the need to protect the child. In this study two mothers spoke of how their children need twenty four hour supervision. These mothers resorted to using closed circuit television (CCTV) to monitor their children while they slept.

"I have a camera there, so I can still sit and chill and do everything, I can't really leave the house or anything" (P1).

"I haven't let him take over my life it's just.... I have to be here with him 24/7" (P10).

Two parents highlighted the need for medication for their children and felt that although they were skilled in dealing with the medical issues as they arose the medical demands made caring all the more constant and intense. They said:

"We had a rough couple months, with seizures every day; we had long days and night" (P1).

"Its 24 hour care ...she is a peg fed. She is on oxygen 24 hours a day, also has problems with seizures you just deal with it" (P2).

One parent explained her child needed a special dietary plan and within a hectic family schedule preparing a second meal for a child became a difficult task. Meal times for this parent were also stressful and time consuming. This parent said:

"It's special diets and the extra time and cost for preparing it" (P6).

No family can ever be fully equipped for the challenges of caregiving for an Intellectually Disabled child according to Glidden & Natcher (2009). They go on to say that the tasks and responsibilities involved can be demanding leading to parents feeling burned out and exhausted from caregiving duties. Simonoff, Pickles, Charman, Chandler, Loucas & Baird (2008) say many Intellectual Disabled children need greater levels of care than children who are non-disabled. In this study the caring role was expressed clearly when one parent said:

"It's such a different type of parenting; it's a twenty hour role" (P9).

This research highlighted that vast amounts of time is spent caring for a child with an Intellectual Disability. This study found that parents who care for their children put their lives on hold. This is illustrated in the following quotations:

"We can never go anywhere together" (P1).

"She is a 24 hour baby, that's what everybody says to me, when they come to the house with a new baby... and they say would you like to feed it or change it, I say no! I have a baby at home" (P2).

"I have no free time; I still have to make sure the house is running" (P5).

"It's all routines now, from first thing in the morning till last think at night" (P6).

"He will need care all his life to be quite honest, you know" (P8).

"It's a fulltime job" (P9).

"We spend all our time caring for him" (P10).

In their study in 2007 Myers & Johnson refers to this caregiving as stressful and challenging for parents. In this study all the parents said that taking care of a child with an Intellectual Disability is one of the most demanding and difficult challenges a parent can face. The parents spoke of the need for constant care and protection for their children. One mother described how her life changed since taking on the main caring role for her child,

"She is totally dependent on us, 24/7; she can do nothing for herself" (P5).

All parents stressed that while caring for a child with an Intellectual Disability is challenging that caring for the child when he/she is extremely ill can be extraordinarily demanding. Carrying out this care is exhausting as one parent described after she had to look for outside help due to the demands of the caregiving. She said:

"I didn't want to leave him. It came about because I was absolutely exhausted and I knew that I needed outside help. I never wanted to give him up for a minute to anybody. I wanted to protect him constantly" (P1).

Another mother described her child as,

"I never stop caring, thinking is she ok, does she need anything even when I'm in bed I still think of her, its fulltime it never stops" (P5).

These results are similar to those of Kenney & McGilloway (2007) who conducted a study on the quality of life of Irish family carers. This 2007 study found that Irish carers were stressed. This stress arose from the nature of caring for the child. Kenney and McGilloway (2007) found that the main source of the stress was from the extensive time required in caring for their loved one which was compounded by lack of support from disability services. They also found that these carers were stressed due to financial difficulties as a result of reduced income. Similar results were reported by McConkey (2005) who found that as the parents continue to struggle in the caring role their ability to continue to do so reduce over time. Such time demands found in this and previous studies suggest the need for more support for parents.

Llewellyn & McConnell (2005) stated that having a child with an Intellectual Disability can be an emotional experience for parents. This was found in this study also. This emerged in particular when parents compared the child with the Intellectual Disability to siblings and other children of the same age.

"My friend's children they were all making their debts last week you know, I was heartbroken, I cried all night ... they were all dressed up and everything and she was sitting in the bed on an oxygen machine" (P2).

"There were times when I thought I couldn't cope" (P1).

In a study in 2005 Hastings said mothers of children with Intellectual Disabilities have shown increased symptoms of depression, increased caregiver burden and increased stress. This stress is evident in the above quote from p1. In this study the parents found it particularly difficult when trying to communicate when the child was non-verbal. All ten parents said they try to understand the sounds and gestures the child makes in order to care for the child's needs. The challenges posed by the non-verbal child were well summed up by what these parent when they said:

“He has no communication, that’s very hard because for me, when he is sick I don’t know how sick he is” (P1).

“When I think she looking for something, I’ll get it for her, is it right I don’t know” (P2).

“She will shout and cry for something, you could try ten different things just hoping one is what she is looking for” (P6).

“She’s a very healthy child. Now...does she have sore throats, does she have kidney infections, and does she have ear aches...you don’t know...because she can’t tell you” (P5).

“We try the communication signs, some work” (P4).

Despite the fact the state provides residential care for children with Intellectual Disabilities, this study showed that parents wanted to parent the child at home for as long as they possibly could.

“I want him to live with us for the rest of his life” (P1).

“She will always live with me, she will never move out full time” (P2).

“We have talked about getting a lone or re-mortgaging the house, to bring people in to help care for her” (P5).

Similar findings by Chadwick, Mannan, McConkey, O'Brien, Finlay, Lawlor & Harrington (2013) showed that families in Ireland still remain the main providers of support for people with Intellectual Disabilities. Families want to and do provide care in their own home for their child. However, the families are stressed with the demands of

this caring role. In line with recommendations from The Value for Money Report (2012) this is an area of the disability sector that perhaps would benefit from a “money follows the patient” approach. A standardised assessment of the individual needs of the child and also the family would benefit. A care package could and should be developed to correspond to the needs of each individual child and each individual family. In the case of the families interviewed for this research the package of care would provide for adequate time away from the caring role for the parents and also of course for siblings and other family members. This demand on parents’ time can have knock on effects and one of these is the impact on the marital relationship which is examined in the following section.

4.2.2 Marital difficulties

According to Beresford (1994) the parental relationship is always of the utmost importance and it is important that parents get time together and time alone to maintain the strength and resilience to provide all these caregiving duties in this study two of the marriages had dissolved due to the stresses and strains associated with caregiving.

“I had to decide that my time had to go towards him, and my husband’s time had to go into the business. I think the pressure in both areas was just too much” (P1).

“We just drifted apart” (P2).

These parents specifically attributed the marital breakdown to the demands of caring for the disabled child. In these cases the needs of the entire family have not been addressed with the majority of time spent caring for the Intellectually Disabled child and this having a negative impact on the marital relationship. When parents are unable to spend time with each other as the above parent said they just drifted apart and go their own way. Linked into this is the topic of isolation experienced among carers and this is addressed in the next section

4.2.3 Isolation among parents

The parents in this study state that at times they are very isolated at home. In fact in this study the dependency needs of the disabled child contributed to mothers feeling helpless, constantly on duty and subsequently feeling isolated. All ten parents described being isolated from outside help at some point. One parent spoke of the lack of parent groups available to her to allow her an opportunity to avail of meeting other parents in similar circumstances. She said:

“And tell each other about different things that they have experienced, and we could help one another along. But there doesn’t seem to be anything out there in that line”
(P7).

More parents went on to say:

“Friends stop coming because they feel sorry for you” (P3).
“You can’t go out, his behaviours are so bad” (P9).

For some mothers the isolation was compounded by a sense of helplessness. One parent described this helplessness when she said:

“There are some days now when he’s really bad, that you just sit down and cry. Because there is nothing you can do” (P4).

As the parents provide care fulltime it can be hard for them to have social lives of their own. As parents described it:

“It’s a twenty four job” (P5).

“Friends ask you out for dinner, when you say you can’t they understand, they will ask again I still say I can’t after a while they stop calling” (P1).

“People just don’t want to know; is it that they don’t understand I don’t know ... but friends drifted away” (P7).

“A day out with friends and their children was difficult I had to plan I had to know everything about the trip to see could I bring her, and the end they stopped asking me” (P6).

In this study parents found relationship with friends changed with the child with the disability was born. For two parents they lost all of their friends. These parents felt this was as a result of the severity of the child’s disability.

“Once he was sick friends backed off” (P1).

“Explaining to them about autism, they didn’t understand” (P10).

One mother reported how she had viewed a family with a disabled child before she had her own child. She said,

“we would be the sort of people that sat watching the television and saying, oh God love them people ... what would you do if you had a child-like that ... And now we sit looking at the television saying, that’s us” (P8).

This is an example of how this parent lacked understanding of the other family. Now she finds herself in similar circumstances and from her comments above sees herself as different and apart from other families who don’t have a child with an Intellectual Disability.

For six parents family life had changed with the birth of the disabled child and this was particularly brought home to them when they saw other families enjoying activities together. Other families enjoying themselves reinforced how much they were missing out. As one parent said:

“But that’s the time when you see the other kids having fun and sometimes I think how much we miss out on as a family because one of us has to be at home, but that’s how it is for us, it’s times like that, but we get on with it”(P5).

This above quote again points to isolation. In this study different factors impacted on the parents’ sense of isolation. These included the constraints of time demands to friends no longer making contact. Friends stopped seeing the parents because of lack of

understanding of the disabled child and therefore the isolation for the parents was felt at different levels, feeling isolated from not spending time with the friends and feeling isolated because friends didn't understand. The parents also felt isolated when they compared their families to others and also when they see themselves as missing out. Jeon (2005) also found isolation among parents in his study and found that this isolation comes from different sources including the amount of time caring for the disabled child, the behaviours presented by the child, reactions from the public and concerns regarding the safety of the child. In this study parents also felt isolated and helpless in relation to challenging behaviour from the disabled child. This will be addressed in the next section.

4.2.4 Challenging behaviors

In this study parents described challenging behaviour as having a negative impact on the family unit. They said this behaviour limited social activities, impacted on time spent with other siblings and generally increased the burden of stress felt by families. Parents described challenging behaviour as:

"Slapping, he becomes very high before a seizure" (P1).

"Shouting and hitting out" (P3).

"Won't sit still for anytime, getting upset and shouting" (P8).

"Hitting out at people, whoever is closest to him at the time" (P10),

"Biting, shouting and banging his head off the wall" (P7).

"Biting himself and will try and bit others" (P9).

Writing in the area of challenging behaviours Hastings (2002) wrote that children who have Intellectual Disabilities and display severe challenging behaviour can cause major disruption within a family unit, resulting in maternal ill health, family breakdown, depression and isolation. One mother in this study told how the child's Intellectual Disability deteriorated over time causing the child's challenging behaviours to increase. This led to a change in the family dynamics as the child became older. It meant that the family couldn't go out as a unit further adding to the mother's isolation.

“Her behaviours are very bad at times; she will hit out at you, through things, shouting, stripping, nights she will not sleep up shouting, its hard at times” (P6).

Writing in this area Grey, Pollard, McClean, MacAuley & Hastings (2010) wrote that challenging behaviour in children with Intellectual Disabilities becomes more evident as the child becomes older. In this study this was reiterated by one parent:

“As he is getting older his behaviours are getting worse” (P10).

Five of the parent’s spoke of their child’s challenging behaviours and the affect it had on the family. Events in the family always had to be planned and nothing spontaneous could occur because of the likelihood of an episode of challenging behaviour.

“In the beginning you know you would die, he would stating shouting ... and you would be like a tomato from head to your toes because everyone was looking” (P8).

“He has challenging behaviour and his behaviours can change dramatically, he may go from one behaviour to another” (P3).

“His behaviour gets very bad before he has a bad seizure” (P7).

“She’s generally known as a runner, if she gets out she is gone. We have to be careful security wise” (P6).

“The more excited he gets the more he will bite” (P4).

“He suffers from self-injurious behaviour” (P4).

“Every opportunity he could take a lump out of his brother” (P8).

Different behaviours were described as challenging by the parents such a shouting, biting, head banging and aggression. In a study of parents in 2001 Emerson described physical aggression, absconding, tantrums, repetitive behaviours and self-injurious behaviour as challenging to deal with. In the current study parents also described these behaviours as difficult to manage. Cheng & Chen (2009) also spoke of similar challenging behaviours displayed by Intellectually Disabled children when their needs were not met due to communication difficulties. In this study the parents found it particularly difficult when trying to communicate with the non-verbal child. All parents said they try to understand the sounds and gestures the child makes and were aware of the inherent challenges in communicating with their child. For example one parent used Lamh (the Irish word for Hand, is a signed communication system) when trying to

communicate with her child. The challenges posed by the non-verbal child were well summed up by one parent when she said:

“He would get very mad over simple things like sitting at the table and he would throw his dinner at us and start banging the table, for no reason” (P1).

Five parents had learned that the child’s behavioural changes were linked to the child’s difficulty in communicating with others outside the home. Another parent had learned that her child’s behavioural changes were linked to his epilepsy.

“His behaviour gets very bad before he has a bad seizure” (P7).

Having an insight into this link between the child’s behavioural challenges and his epilepsy was very helpful for this parent in preventing challenging behaviour escalating. From this study it became apparent that parents were finding it difficult to deal with the challenging behaviours and this is another area where help, education and support would be beneficial.

As well as all the above mentioned stressful and emotional demands on parents there are also demands from other directions. In the next section changes to the structure of the house, financial challenges and concern for the child’s future are discussed.

4.2.5 Changes in the structure of house

In this study all parents emphasised that as the child became older changes had to be made to family life and the home. One parent spoke about the practical problems having a child with an Intellectual Disability brings. She said:

“We have the bedroom downstairs. We have a lot of equipment...standing frame...we had to adapt the shower, you know put in a wheel in shower” (P5).

Pilowsky et al (2004) also wrote about these structural changes saying that following the birth of an intellectually disabled sibling the rest of the family may have to manage

with changes in the family unit, such as structure and activities. In relation to changes in the family routine in this study parents said:

“We were lucky we have the bedroom downstairs, when he was small he was in an upstairs bedroom but as he got bigger, he became too heavy to be carrying up and down the stairs” (P9).

These are another few examples of the changes and challenges faced by parents in caring for a child with an Intellectual Disability.

4.2.6 Financial demands

Two of the parents stated that they had significantly less finance now than during the Celtic tiger years. This resulted in financial hardship for all the family. These parents said:

“We never had to worry about babysitters as we had the money to pay for them” (P1).

“We are considering re-mortgaging the house to get us by” (P5).

Another parent noted:

“It’s getting more difficult to access services” (P1).

In the current economic climate it is likely that this financial challenge will continue and perhaps even worsen and thereby increasing the stress burden on parents. One parent alluded to this when she said in relation to financial issues:

“What will the future hold for us” (P8).

So what does all this mean? Parents reported stress, tiredness, constrained by too little time, concerns for other family, difficulty in understanding the non-verbal child and many more challenges. They also reported feeling isolated and not understood. It is important for these families that they have access to a comprehensive service that addresses all their needs. These needs include support with the caring role, supports to

reduce the sense of isolation, skills to deal with the challenging behaviors. Care packages that address all the needs of the child with the disability but that also take the needs of the whole family into consideration is important. Although the needs of the child are paramount all children should assess in the context of the wider family.

4.2.7 The child's future

The majority of parents in this study said they will provide care for their Intellectually Disabled child for as long as possible. However, most parents were also aware they would not be able to provide this care indefinitely as they advanced in age. All parents voiced fear and sadness for their child's future, worrying about who would care for the children when the parents were gone or were unable to cope. All parents felt that the care for their child should not be the responsibility of family or siblings. This is illustrated in the following quotes:

"Well he will need care all his life now, to be quite honest, and I couldn't see myself leaving the burden on his older brother" (P8).

"And I have told the two girls here that it's not up to them to mind her and I don't want them to mind her, they will have their own lives to get on with" (P6).

Nine of the parents spoke of their worry for future care needs for their children. Who would care for them, what would the standard of care be like?

"It's a massive worry, like it is a huge thing, and it's always in the back of my head, always" (P5).

"I do worry about what will happen to him" (P10).

"She will have spent all her life with me caring for her, and if she has to go into fulltime care will her care be the same as at home with me" (P2).

"I'm so worried about it I know its years away, but I still worry" (P4).

Parents had not thought of alternative care although aware of their limitations in terms of not being able to provide long term care and also not wanting siblings to look after the Intellectually Disabled child. When asked, all parents admitted that they had not thought deeply about the long term care for their Intellectually Disabled child and had only really contemplated short term care.

“I haven’t really considered down the road, I am just about coping now” (P1).

Most parents had not carried out any research into possible future care arrangements for their child and explained that they had not contemplated this scenario.

“No we have not thought about it” (P9).

“I don’t think about it,” (P3).

“He is still young” (P1).

Nine of the parents talked about their sadness regarding the future of their child. Sad that the child would not be able to partake in normal life and sad that as parents they would not be able to provide care for ever.

“I’m constantly felt that I am... I am sad and really dread what’s going to happen” (P2).

“I’m sad as we are a family but sad that we can do very little together” (P5).

“It would be nice to think she could do thinks girls her age do but she can’t,” (P3).

Keenan & McGilloway (2007) says that planning for the future care needs of the child with an Intellectual Disability is important. In this study the parents were sad when thinking about their children’s future but were not actively planning for future care arrangements.

The next section will look at the impact on siblings.

4.2.8 Impact on the siblings

Eight of the parents in this study highlighted how family life had changed with the caregiving duties for an Intellectually Disabled child. The parents spoke of endless routines for the child and medication having to be monitored but they also spoke of the positive affect the disabled child had on the family. One parent described the positive impact on the family when she said:

“He’s the life and soul of the family” (P1).

Eight parents said that raising non-disabled children alongside a child with an Intellectual Disability was rewarding. A number of parents stated:

“They do love him and will do anything for him” (P1).

“They do understand him,” (P4).

“It’s just the two of them brothers and the oldest one will always look after him” (P8).

“They all accept him; you know he is as normal as anybody else” (P10).

In this study the parents said that having a sibling with an Intellectual Disability impacted positively on the other siblings. Strohm (2002) found that the siblings of Intellectually Disabled children are usually expected to mature sooner than their peers, as they need to care for themselves, while their parents provide care for their Intellectually Disabled sibling. Similar findings were obtained by Meyer (2000) who suggested that siblings who have grown up with an Intellectually Disabled child may have a greater level of understanding and development than peers of a similar age. He also goes on to say that siblings of Intellectually Disabled children have a greater level of understanding and empathy towards others due to the care giving role that they have provided to their sibling from an early age. In this study parents said:

“My other son is great he will help out with caring, I know he had to grow faster than his friends” (P1).

“I know it does hurt her deep down that so much time goes to him” (P9).

“They all know that I give extra care to her but never have they said anything about it” (P5).

“His brother just, says that he knows he needs that extra time, he is very understanding of it”
(P8).

According to Berk (2001) siblings spend time with each other playing and helping one another and taking care of each other if a parent is momentarily absent. It is unlikely for a sibling to contemplate that they will consistently be required to act as a caregiver for a non-disabled sibling. This, however, may change when a sibling with an Intellectual Disability is born within a family. Strohm (2002) suggests that the older siblings will be expected to provide care for the Intellectually Disabled sibling. In this study parents acknowledged this assistance from older siblings but worried that this caring role would affect the siblings’ childhood experiences. Parents felt that the siblings had to mature quicker due to the caring duties to the disabled child and also because the parents had less time to parent the non-disabled siblings.

“My other son, he felt the responsibility was on his shoulders, the fact that his Dad left as well. And he actually would have taken on a lot of the responsibility. He’s feeling the burden of it also. And I try not to put too much on him” (P1).

“It’s hard on the rest of the family” (P5).

“To this day it still affects her... that jay always comes first” (P6).

“His sister took a wide berth. She felt as if all the responsibility would land on her shoulders”
(P1).

Even as the parents worried they also acknowledged that the siblings become more independent at an earlier age than their peers which they viewed as a positive.

“He did grow up fasters, when we had to go to an appointment in Dublin he would come with me, I don’t think at the time I realised how much of a support that was for me, I don’t think I could have done it on my own” (P1).

According to Pilowsky et al (2004) following the birth or diagnoses of an Intellectually Disabled sibling, the non-disabled sibling may have to manage with changes in family unit, such as structure and activities, feelings of guilt and shame, loss of their parents’ attention and more episodes of parental stress. An example of this concern was apparent

where one family had sent the non-disabled sibling to boarding school in order to avoid the disruption in the home as a result of the disabled sibling.

“My oldest daughter she felt it the most from early on in to the diagnoses I could see her change, today this day, she is jealous of the attention her sisters gets “(P6).

Another mother had a similar situation with her oldest daughter

“As she got older she could see we were spending more time with him, so she was pushing the boundaries with us” (P1).

Doppelt et al (2004) found that a sibling with an Intellectual Disability may result in increased levels of stress for the non-disabled siblings and this can have erratic effects on their psychological wellbeing. This study concurs with these findings as according to some of the parents interviewed siblings share the same feelings parents felt at the time of diagnosis.

“They felt a responsibility towards their sister” (P5).

“It was coming up to exam time, she was stressed, and we were stressed she worried about him” (P1).

At times feelings arise because the parents withheld information from the siblings to protect them. Intellectual Disability and stigma can often be linked in people's minds due to lack of knowledge, fear, embarrassment or numerous other reasons Hewstone (2003).

In this study one sibling felt she could not speak openly to her peers about her Intellectually Disabled sibling as she would have to explain about his special needs and this embarrassed her.

“His Sister was telling me that she doesn't like talking about her brother to other people and she didn't want to invite her friends around because, then she has to explain that he has special needs and I think she felt embarrassed”(P4).

Strohm (2002) found that older siblings often felt resentment and negatively towards a disabled child. Strohm (2002) also goes on to say that sibling's reactions placed extra

stress and worry on the parents. In this study three parents acknowledged that the non-disabled siblings were embarrassed by the Intellectually Disabled sibling due to their peers' lack of understanding of disability. As parents said;

"His Sister was telling me that she doesn't like talking about her brother to other people because then she has to explain that he has special needs" (P4).

"Our bathroom door is always locked, when his brother's friends call around he feels he as to explain why it's locked and why we do things different in the house"(P8).

"My daughter said no point asking friends to call" (P1).

Children suddenly must adjust to a brother or sister because of their condition may require a large portion of family time and support. Each child's reaction to having a sibling with a disability will vary depending on his or her age. The responses and feelings of the non-disabled sibling toward the sibling with a disability are not likely to be static, but rather tend to change over time as the sibling adapts to having a brother or sister with a disability.

In order to make space for her other children one parent said:

"For the other boys we had to build on to the house so the rest of the family could have a room for friends and to watch the TV" (P10).

As can be seen from the above siblings play an important role in the care giving duties for their Intellectually Disabled sibling. They go through the same stresses as their parents and they often have less free time due to care duties to their Intellectually Disabled sibling.

With all the different and varied demands placed on a family caring for a child with an Intellectual Disability it is important the family get as much support as possible and from as many sources as necessary. The following section will discuss the second main theme from this research, the supports and services available to parents from grandparents and from respite care.

4.3 Supports and services available to the parents

4.3.1 Grandparents

This study found families received informal support from grandparents. This support took the form of emotional support to the child and a caregiving support to the grandchild. This support was mainly provided by maternal grandmothers. Similar results were found by Hornby & Ashworth (1994) in a study of parents of children with Intellectual Disabilities. They also found that grandparents, predominantly maternal grandparents helped with childcare. The researcher found that within this study, this support only lasted a short period of time, due to the natural progression in age and ability of the grandparent. One mother said,

“My mother was brilliant with her when she was younger, but while my daughter was getting older so was my mother” (P3).

Four of the parents noted that their own parents helped initially with caring duties at some stage of the child’s life. One mother said,

“The grandparents were brilliant, I wouldn’t let anybody else mind her at the time, because ...she’s was so delicate and we were so afraid, as she got bigger and stronger and needed more care and as my parents were getting older, I understood they could not help anymore”(P2).

However, only two of the parents said that their parents still continued to provide care.

“My mother lives across the road, so she is in and out helping” (P4).

One mother spoke of the fact that her in-laws didn’t fully understand their grandchild’s Intellectual Disability and felt uneasy approaching the subject. This mother said

“I don’t think my husband’s parents fully understood, what it was, or the implications of it” (P3).

Fears from one mother encouraged her to source outside help as the child's grandparents became older and the child became bigger and stronger new caring arrangements had to be made. One mother said

“My father is disabled and I was afraid that she would floor him if she decided to take a wobbly” (P9).

Grandparents can be a valuable resource in the care of the Intellectually Disabled child. However, as MacDonald & Callery (2004) state that as the child becomes older it may become too much of a responsibility for the grandparents to provide a caring role. This may be because grandparents, for example, are themselves getting older or because carers do not want to “put others out”. As well as support from grandparents the parents in this study also sought support from respite services. The next section will now present the findings and discussion on respite care under the following headings: A form of support, Concerns about availing of respite, Issues with service delivery, Parental knowledge and involvement with the service.

4.4 Respite Care

4.4.1 A form of support

All parents felt drained mentally and physically with the care demands of their Intellectual disabled child. They felt that over time the toll of caring was detrimental to their mental health. One parent aptly sums this up when she said.

“Because if I didn't let go I was probably be the next one to have a nervous breakdown” (P1).

All ten parents acknowledged that they needed support in providing care for their Intellectually Disabled child. They felt that if the child was to remain in the family home then they as parents needed breaks to recharge. As one parent said:

*“Yes, it gives us a chance to kind of...refuel and get ready for him to come back in”
(P8).*

All the parents availed of the services of respite. This service was a purpose built unit consisting of six beds situated in Sligo town. The respite care facility was staffed with Intellectual Disability nurses and supporting health care workers. Nine of the parents acknowledged the benefit that respite care had on the family. These parents felt that this resource was invaluable and contributed greatly in a positive way to family functioning. One parent described the treats they could partake of when the child was in respite.

“We might get a video and we can all sit down as a family and sit in the sitting room and get a take-away, you know it’s a real treat” (P6).

Other parents go on to say:

“I can relax...and I am not on edge. And we all go out for dinner as a family. And it’s not right to say that...but it’s just a nice time” (P10).

“But it’s great not to have a routine once every few weeks” (P5).

Only one mother highlighted that having no routine was upsetting. This was because the parent provided full time care for her child and expressed that she becomes scatty without it. She said:

“You have no routine when she is gone, so much revolves around her mornings, evenings, night all about her so a few days off and you’re all over the place” (P5).

In this study, the majority of parents didn’t involve their son or daughter with Intellectual Disabilities in the process of deciding to use a respite placement. The reasons included the age of the child and the level of the Intellectual Disability.

“It was offered to me; if I told him he would not understand” (P1).

“She was young when she went to respite first, she would have no understanding of it” (P6).

“She would have no understanding” (P5).

“He wouldn’t have understood” (P10).

However, it was important for parents that their child was happy in respite care. When asked if the child with the Intellectual Disability was happy in respite care all parents said that their child was relaxed and much happier on return to the family. The happiness of the child on their return to the family home encouraged their parents' decision to continue to avail of respite care for the child.

"Yes he is happier when comes back home, like he has had his breakaway" (P7).

"When she knows she is going to respite she wants her bag to pack it and be ready" (P6).

Eight parents were satisfied with the quality of respite care. They based their decision on the fact that their child was happy to attend respite care. The father highlighted:

"He loves it, it's a great service and he is happy to go for the few days, and happy on his return" (P10).

Another parent noted that their child met other children and experienced life outside the family home while learning independence.

"I have to say, it's a very positive experience and it's more of a social outing more than anything else, she calls it club, she can go and meet friends and get away from the house" (P9).

Adding to this other parents said,

"We see this as a way of independence for him, that he might gain skills that will help him later on in life" (P3).

"They get to go on Picnics" (P7).

"He goes on bus spins and mixes with children his own age" (P1).

As can be seen from the above statements the parents believed that respite time was a positive experience for their children. They based this judgement on their observations of their children, that they seemed happy to go to respite and that they learned new skills there. However, the parents had no input into what the child did in respite (as will

be addressed later) and therefore there were no objective measures against which to gauge the parent's observations.

Although the parents were happy to use respite care and saw it as beneficial to the child using it and to the family as a whole they also had reservations about using it. The next section will address this.

4.4.2 Concerns about availing of respite

Despite the fact parents felt they needed support nine of the parents initially didn't want to place their child in respite care because they felt that nobody could care for their child the way they did. But they also felt that they themselves needed a break if they were to continue to offer their child high quality care. Parents said:

"It was a break for a day or two, spend time with the other family" (P7).

"You feel at the end of the day no one can mind her, the way we mind her" (P5).

"I'm afraid that he could be hurt when he's there" (P1).

"I needed the break a few nights sleep" (P6).

The parents also initially did not want to hand over the care of their child to a professional body because of the on-going news coverage of institutional abuse. Parents felt that their child might be abused. As these parents said:

"My biggest fear is somebody will abuse her when I am not there at night in one of these homes, emotionally...physical...sexually everything in one of these homes" (P2).

"Because I always had this thing in my head that supposing somebody abused him because he can't tell us...I mean physically or mentally abused him in any shape or form" (P1).

Although the parents had the concerns as voiced above they had very little knowledge about the respite centre and the activities that occurred there (as will be discussed later). The parents also had mixed feelings about placing their child

in respite care. As well as acknowledging the benefits to the child the parents felt sad. This is illustrated by parents when they said:

"The first time it wasn't easy ...you feel like you are giving away the child, but as time goes on, we just found it normal, on the other hand we see it as independence" (P3).

"The first day he went to respite, all I could think of was what I have done, letting him away for the night" (p8).

"I was very sad I needed the break and she did to, away from each other" (P6).

"The house was dead without him and I cried" (P4).

"So upset, when she went first" (P2).

The initial worries that parents felt when their child entered a respite placement were lessened when the parents noted how the placement impacted positively on the child as found by Savage (2002) who says that caregivers within the family are always positive about respite care. Some of the parents felt that the child gained valuable social skills, independence and new experiences which they may not have experienced within the family unit.

4.4.3 Issues with service delivery

When asked for their opinion of respite care parents spoke of the lack of availability of respite placement and the short notice of available space, parents spoke of challenging behaviours that their child had learned in respite and the lack of opportunity for interaction among the parents of the Intellectually Disabled children.

"It started with banging his head" (P1).

"I never got introduced to other parents" (P2).

"Don't know any other parents who use respite" (P8).

The amount of respite offered and the scheduling caused concern for parents, with little notice being offered to parents of respite availability. This short notice prohibited them from organising themselves and siblings to make the most of the respite break and to organise activities that they would not be able to partake in when the Intellectually Disabled child was at home. Eight of the parents felt that respite was offered with little

notice. As places became available they would receive a phone call offering a placement for the next day or even a placement within the next few hours. Parents said:

“We have to fit around respite. They don’t fit around us” (P1).

“I get a phone call, there is a place free and do I want it” (P7).

“We don’t get enough, a night or two here and there” (P10).

“It’s great when we get respite would be nice to get some notice” (P8).

We do receive respite, but not enough you need a few days together not just one “(P6).

“Only one night I need a few nights together” (P1).

King & Rosenbaum (2001) said that parents valued services which were flexible, readily available and ones which provided a high quality of care. In this study the services didn’t meet the criteria of flexibility or being readily available.

Seven of the parents said that although their children attended respite with other children the parents didn’t get the opportunity to meet the other parents. Parents said that this was frustrating at the time as it would be supportive to meet parents in similar situations.

“I have never been asked or introduced to other parents using the service” (P1).

“I have never met any other parents from respite” (P8).

“I’m unaware of what he does for the time he’s away” (P1).

All the above suggests that parents felt they were not getting the best possible benefits from the respite care offered, it wasn’t flexible, readily available and it dealt with parents in isolation from one another. The parents in the study would have welcomed the opportunity to meet each other and to support each other

4.4.4 Parental knowledge and involvement with the service

When asked about the activities available to the children while attending respite care the parents were unaware of what occurred there. This is illustrated when they said:

"I'm not sure what he does in there" (P1).

"I don't know" (P8).

"I'm sure they do things, when I call they say she is happy" (P2).

"Gets to play with new games" (P10).

"I still have no idea if he behaves or not" (P9).

When asked how they were involved with the respite service the parents indicated that other than arranging the time for the child to attend they had no other involvement. Parents said:

"I get him ready in the morning, he goes off to school and the respite bus will pick him up from school" (P4).

"She gets picked up from school" (P6).

"I drop him down to respite" (P1).

"He goes from school" (P10).

The majority of parents spoke highly of their first contact with the manager of the centre and of how they found the manager approachable.

"She was very nice and helpful" (P2).

"So nice, telling me she would be fine" (P6).

"Such a lovely woman, she told me to call at any time, that there would be somebody there" (P8).

"Not to worry that it was a break for us too" (P10).

"Go off and enjoy ourselves" (P5).

"Very understanding" (P3)

However, other than meeting the manager the parents has no other contact with the service.

Parents had no knowledge of the care staff and the different grades employed at the respite centre. Neither were the parents aware if nurses worked there nor were they

aware of any other staff (cook, cleaner). They had no knowledge of the experience and qualifications of the staff members. Parents were unaware of which staff members were on the roster or what activities were planned. Parents said:

"I don't really know what goes on, but I know he's happy" (P8).

"I don't know I know that there is always two or three staff on" (P4).

"There is always a few people working" (P2).

"It's mostly woman who work there" (P9).

"It's always the same staff" (P1).

It is clear from the above findings that parents used respite care as a break for themselves from the constant caring duties to the child with the Intellectual Disability. However, how the child was cared for or how the child's individual needs were catered to was unknown to this set of parents. There was no continuity of care between home and the respite service. The researcher found not relevant literature in this area.

4.5 Conclusion

In conclusion, the main findings from this research were:

Parents felt stressed with the time demands of caring for their child with the Intellectual Disability.

This stress was experienced in different ways including feeling isolated, being concerned for the other siblings, having a negative impact on the marital relationship and financial demands.

Parents availed of support from their own parents and this support came mainly from maternal grandmothers.

This support however diminished as the grandparents aged and as the children with the Intellectual Disability aged.

The parents valued respite care and saw it as a means for them to get a break and recharge.

When the parents initially began to use respite care they had anxieties and concerns about doing so. They feared their child might be abused among other things.

Parents often didn't receive respite when they needed it most. It was offered as it became available in the centre and was not given in response to the needs of the family. It was not planned from the point of view of the needs of the parents.

Parents had contact with the manager of the centre but had no knowledge of anything else about the centre. They were unaware of who worked in the centre or what activities were carried out there.

In the next chapter, chapter five, a summary conclusion of the whole thesis is presented with recommendations and suggestions for future research in this area.

5 Chapter Five: Conclusions, Recommendations and Directions for future research

5.1 Conclusions

To conclude, this piece of research was carried out in order to get a better understanding of the issues facing families who are caring for a child with an Intellectual Disability and their experiences of using respite care. The research started with an examination of the published relevant literature. This review began by looking at how our understanding of Intellectual Disability has evolved over the centuries. This evolution witnessed a shift from viewing the person with the disability as someone excluded, vilified and blamed for the disability to a culture that now embraces diversity and sees the person with the disability as equal with the same rights as everyone else. The review also examined the medical model and the social model of service delivery. The medical model viewed the person with the disability as someone to be fixed. The social model views the person with the disability in his/her totality and the disability is not to the forefront and the person is not defined by it. The social model is one that is inclusive and the person with the disability is in charge of his/her own life.

The literature review also listed some demographic information pertaining to the number of people in Ireland with a disability and information also on the number of carers in Ireland who care for a relative with an Intellectual Disability. It also looked at the impact of the caregiving role within the family, focusing on the impact on parents. On examination of current literature the researcher found that the challenges parents faced had different impacts on both parents. Mothers, for example often felt stressed and isolated whereas fathers coped by staying away from home. Stress in the literature was also linked to isolation. This isolation arose from the time spent in caring for the child and hence less free time for the parent him/herself. Another aspect of the literature was the stress experienced by siblings and the shame and blame that siblings felt. The literature also stressed the positive aspect for siblings in terms of their leadership skills and their maturity and independence.

The literature review also examined supports available to parents. Grandparent support and support from respite care was explored. The literature indicated that parents gained support mainly from maternal grandmothers. The literature regarding respite care

indicated that it was a valuable resource for parents and was seen by parents in a positive light and helped relieve the burden of fulltime caregiving. However, literature from the Irish context indicated that the amount of respite care available was wholly inadequate to meet the growing demands for this service from parents of children with an Intellectual Disability.

Relevant legislation from an Irish perspective was also included in the literature review.

In conducting this research the researcher chose a qualitative approach as the researcher believed this was the best method to learn of the personal and unique experiences of the families. A purposeful sampling technique was employed and ten parents participated in the study, all of whom have a child with an Intellectual Disability and who avail of Respite Care Services. The sample consisted of nine mothers and one father. A semi-structured interview was conducted with each parent and the data was analysed using thematic analysis.

The results showed that parents viewed the care of a child with an Intellectual Disability as both a demanding and a rewarding vocation. They saw the child as the centre of the family, the life and soul of the house. They, however often experienced stress and felt they were isolated in their caring role. The results also show that this stress came mainly from the time required to care for the child with the Intellectual Disability. The results found that this time demand had negative consequences for some parents in terms of their marital relationship thus causing stress. The results also indicated that the parents found it difficult to deal with challenging behaviour in the child and they saw this as adding to their isolation. The results also found that parents were concerned about the other siblings in terms of the responsibility placed on them and in relation to their overall adjustment to accepting the sibling with the Intellectual Disability. In contrast parents described the child with the Intellectual Disability as the life and soul of the family and even though the role of a caregiver is very demanding that they would not want this to change.

Other findings from the study showed that parents received help mainly from maternal grandparents but that this help dwindled as the grandparents and the children grew

older. This lessening of support occurred as the care demands of the child increased with age and the grandparent's ability to respond lessened as they aged.

Other findings from the study showed that parents availed of respite care and saw it as a valuable resource for them. However, they didn't receive an adequate amount of respite time, the respite was offered as it became available and not in response to the needs of the child or the family. The parents were given short notice when respite became available. Although helpful to get the respite the parents felt the short notice didn't allow them to plan for other activities they could have been able to do when the child with the disability was in respite. Some of the other findings from the study were that parents were concerned initially when sending the child to respite in case the child was abused there. Despite this they were totally unaware of what actually occurred during the time their child was in respite care and that they were also unaware of the qualifications of the staff offering the Respite service. The parents had no involvement in anything to do with the planning or the delivery or evaluation of this service. The findings showed that they believed it was working well because their child was happy there. There were no other criteria used to establish its effectiveness in any way.

The overall conclusions from this research are that these parents felt under stress from the demands of caring for a child with an Intellectual Disability, they valued respite care but were not involved in any aspect of its organisation or delivery, and that in its present format was not meeting the needs of the parents and the parents were unaware of what happened in respite so whether the needs of the child were being catered for nor not is not known from this study.

The results of the study are important in terms of the social care profession. They point to the fact that parents' experiences aren't known and that services therefore, aren't facilitating parents. The social care profession can benefit by increasing its knowledge and awareness in this area and by making sure that the needs of the child with the Intellectual Disability are taken care of together with the needs of the whole family. This research has highlighted this gap in the service. It has also highlighted how excluded parents are from any form of participation in terms of the service they receive for their child. In this study the child with the Intellectual Disability was also totally excluded from having a voice in the care they received. The social care profession needs

to address this and advocate for the rights of the child to a service that listens to the child and responds to the individual needs of each child.

5.2 Recommendations

On the basis of this piece of research the following recommendations are suggested.

Parents viewed respite care as a valuable resource for them but it was limited in its delivery. It is suggested that the parents are involved in the planning and delivery of this service. The respite centre will have a certain number of hours to allocate to parents so a system of prioritising these days drawn up in consultation with the parents would be beneficial. Parents then would have some input into when exactly respite became available to them. This could give the parents a measure of control in terms of using this time away from caring for the child with the disability. They could then plan ahead of time so that they could get the best use of this free space.

Parents in the study indicated that they felt isolated in their caring role. They said friends drifted away from them and they felt other people did not understand their position. These parents also said they would like to make contact with other parents using respite as they saw this as a means of support. The respite service could take an initiative around this. It could check with each parent who uses the service to see if he/she wished to take part in such an initiative.

The parents knew nothing about the respite centre and nothing of the activities that took place there. There was no continuity in any care plan for the children using the service. It is suggested that parents become involved in the centre to a greater extent, that they have meetings with the manager and staff there and learn about all the activities and interventions that take place there. The parents and centre should also make sure that the child's individual needs are catered to and that each of the children has an individual care plan. This plan needs developed with the parents, child where possible and the centre. If the child is in respite during school time then there needs to be some continuity between the child's educational needs and its care in respite.

5.3 Directions for future research

This piece of research has highlighted the shortfall in research into parents' experiences of caring for a child with an Intellectual Disability.

Further research in this area is needed. The experiences of parents in caring for a child with an Intellectual Disability require more comprehensive research. A larger sample is required. More fathers need to be studied to understand more fully their experiences. The perspective of parents from different ethnic backgrounds (in an Ireland that is becoming more diverse) needs to be examined. It would also be very beneficial to explore the experiences of different family constellations.

Research that incorporates a wider geographical area is also required. Focus on different factors that might influence the role of caring also needs exploration. Examples of this would include employment status in the family, the number of other siblings, other stressors in the family, rural/urban comparisons. International comparative research would also be very enlightening.

In my study the experiences of parents in caring for a child with an Intellectual Disability were explored. The sample was small and the parents' experiences were explored irrespective of the age of the child being cared for. Further research could address this. Are there/what are the different challenges faced by parents in rearing different aged children with an Intellectual Disability?

Since this is an under researched area there are numerous facets of this area that could be explored and researched further which would add greatly to our knowledge in this area. Such knowledge could greatly enhance the development, delivery and evaluation of services in the disability sector.

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Appendices

Appendix one

Letter to Principals/Respite Care Managers

Dear Principal/Respite Care Manager

September 2012

I am studying in Sligo Institute of Technology for a research masters in the area of Intellectual Disability. The main focus of the study will be an examination of parents'/guardians' experience with respite care and their experiences of caring for a child with an Intellectual Disability.

I am hoping to obtain research material relating to the family's use of respite care and how the families and children benefit from this care. I also hope to ask families about the demands and challenges of rearing a child with an Intellectual Disability. I am hoping to interview parents/guardians who have children under the age of eighteen with an Intellectual Disability. Their participation in this study is completely confidential, anonymous and voluntary.

I am asking your parents' committee for permission to conduct this study with the parents/guardians of children who have an Intellectual Disability and who attend your school/respite care facility. If the parents' committee grant this permission, is it possible for the committee to contact the parents/guardians concerned with the enclosed information or if not, is it possible for me to contact the parents/guardians directly if I obtain the relevant consent from the committee?

Thank you for taking the time to read this and I hope that you can accommodate me in my research. Contact details can be found below.

Kind regards,

James Dunne.

Ph 08*-*****

Mail S000*****

Reply by S.A.E

Appendix two

Letter to Guardians/Parents

Dear Parent(s)/Guardian(s),

September 2012

I am studying in Sligo Institute of Technology for a research masters in the area of Intellectual Disability. The main focus of this study is to explore family life and your experience of using respite care.

It would be of great benefit if you would consent to participate in this study, as your views and experiences as a carer of a child with an Intellectual Disability is of great interest and value to my study. Your participation is completely confidential, anonymous and voluntary and you may opt out at any time. The completed masters will be available in the Sligo Institute of Technology.

The information will be obtained by face to face interviews which will last approximately thirty minutes, where I will use an audio recorder for the purposes of information gathering within your home or in a location of your choice. You are free to contact me at any time for clarification or for any other reasons related to this study. The information obtained from the interview will be treated in strict confidence.

CONSENT

I agree to participate in this study and fully understand the purpose and nature of it.

Name:.....

Contact Number.....

I agree to have the interview audio recorded.

Name :.....

Date:

Kind regards,

James Dunne

Ph 08*-*****

Appendix three

Interview Guide

Introduction:

Firstly I would like to thank you for agreeing to take part in this interview. I will be recording the interview and if need to I will be take some notes as well - I hope that's OK with you?

As stated in the letter, all we are going to talk about is confidential and your name will not be used on any of the information gathered.

If you feel uncomfortable at any time answering any of the questions say so and I will move on to the next question. You are free to withdraw from the interview at any time. Your involvement in this interview is purely voluntary. At any time you do not understand any questions or you would like me to repeat a question please be free to ask for clarification.

Do you have any questions before we start?

First I am going to start off by asking you questions about your family and family life

- Tell me about your family in general
- How many children do you have and what are their ages?
- Who also lives with you in the house besides your children?
- Do you work outside your home?

Can you tell me about your child with an Intellectual Disability?

- Name, age and personal traits
- What is the diagnosis of your child and what is the level of their Intellectual Disability?
- What level of support does your child need?

- What services such as schools and other facilities does your child attend?
- Any special requirements for assisting the child?

Can we talk a little about Caring for your child?

- What are the routines and duties in regards to caring for your child?
- Who is the main caregiver to your child?
- Has any other family members provide care for the child?
- Tell me what is involved in providing care for your child?
- What outside help from family, friends and others do you get in terms of caring?
- What are the positive aspects of caring?
- What are the difficulties of caring?

I am now going to ask you some questions about the services your child attends, such as respite care

- What are the services available to you child?
- How are you involved within these services?
- Have you an opinion of the services
- How often do you use respite service?
- Is your respite care planned or on an emergency bases?
- Can you tell me what activities your child participates in, while attending respite?
- Does respite allow you to mix with other families in similar circumstances?
- Do you feel that this has benefited you, as these families understand your situation better?
- Has family life improved as a result of respite?
- Do you feel that respite is an extension of your family life?
- What activities for children with the similar Intellectual Disabilities does your child attend?

I am now going to ask you some questions about your relationships within and outside of your family.

Can you describe your relationship with family members and friends?

- Tell me how significant these relationships are to you.

- How much supports do you receive from family and friends?
- How do you spent time with family and friends
- In what ways does having a child with an Intellectual Disability affects the way you relate with family members and friends?
- can you tell me a little about your relationship with your child?

Finally

- How do you see the life of your child?
- Can you tell me how your life as a parent/caregiver affects how you
- Other family members?

Is there anything more you would like to add?

Thank you very much for taking time out of your day to meet me.

Appendix Four

Reflection on the process of undertaking this research thesis

This thesis allowed me to conduct my own research project from start to finish. It was a rewarding and intellectual challenge. It involved disciplined thinking and inquiry and problem-solving techniques. It also required a lot of application and persistence.

Though it was difficult at times to motivate myself to do the work, on the whole I enjoyed the research and found that the work was much more manageable than I thought it would be. Researching and reading started out exciting as I learned about the Intellectual Disability field. It however also posed challenges for me. Writing in an academic format I found challenging. I also found it a challenge to organise my work in a logical and consistent way. These skills have improved greatly. Researching relevant published work was also a bit of a challenge. There is little published in this area in Ireland.

I learned how difficult it can be to access people to partake in research. This can be frustrating particularly when there are a lot of refusals to partake. I had to learn to adjust to these disappointments and continue with the work and this was a challenge. My motivation was challenged and I had to overcome this to continue with the work.

While researching this field, I gained an insight into the importance of family in regards to Intellectual Disability. I feel that I had a strong rapport with the parents and that they felt comfortable in divulging very personal and confidential information to me. I enjoyed conducting interviews. It was a privilege for me that parents agreed to partake in the study. It also was an inspiration for me and kept me motivated when they described the challenges and demands they face on a daily basis. This research gave me a really valuable insight into the lives of these parents and this has impacted very positively in my own work. I now have a much better understanding of parents' perspectives and this is very beneficial to me. I enjoy talking to people, asking them questions, and exploring their experiences. I learned that while gathering the data was interesting it was a much more complex task to assemble it in a coherent flowing document which would be easy to read and have a natural flow.

I can now look back and realise that this experience has helped me both as a student and as a young professional. Research and writing skills are a valued resource in a professional setting and I now feel much more confident in my writing abilities and my research skills. Presentation skills are also crucial in almost any professional setting and I feel the presentation aspect of this thesis has helped to develop my skills in this area.

While reflecting on my experience of writing the thesis, I came to the realisation that I truly enjoyed the process. I am the type of person who loves to learn and always seeks to gain more knowledge, both academically and professionally. I am especially passionate about the Intellectual Disability field and intend to continue my career in this sector.